Parents of Children with Disabilities: Exploring the reasons for seeking help for sleep problems

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ABSTRACT

Background: Sleep problems in children with disabilities are highly prevalent and impact upon the child's, their parent's and their family's emotional and physical well-being. Research suggests that cognitive-behavioural interventions based on parental involvement can be effective for children experiencing these problems but there appear to be challenges in engaging parents in services and completing interventions. Research into this area has considered influences on parental help-seeking for sleep problems but has been limited by a focus on barriers to help-seeking and a lack of qualitative approaches. The aim of this study was to explore parents' experiences of sleep problems, the ways in which they understand and talk about sleep problems and what influences seeking help for sleep problems. **Method**: Semi-structured interviews were conducted with ten parents of children with disabilities and sleep problems who had been referred to a specialist sleep service. Thematic Analysis (TA) of the interviews was underpinned by a critical realist epistemology and informed by Braun and Clarke's (2006) six-phase model of TA. **Results**: Five themes, which seemed to be relevant to this group were constructed through the analysis: 1) Identifying Sleep is a Problem describes how parents came to recognise sleep as a problem, 2) How to do Parenting describes how parents were influenced by ideals of parenting, 3) Escalation of the Sleep Problems: Eliciting a Help-Seeking Response describes the emotional experiences leading up to help-seeking, 4) Can you get Help for Sleep Problems? describes the limited knowledge parents had of services, 5) The Context of Parenting a Child with Disabilities refers to the overarching influence of this context. **Conclusions**: The findings are discussed in context with reference to the literature on parental help-seeking. The implications for future research and clinical practice are discussed in respect of the strengths and limitations of the study.

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ACKNOWLEDGMENTS

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1. INTRODUCTION

1.1. Overview

This thesis is a qualitative exploration of parental help-seeking for sleep problems of children with disabilities. Research suggests that the offering and uptake of interventions for sleep problems is relatively low, despite sleep problems being prevalent among children with disabilities. This chapter sets out the context for the study with reference to the nature of childhood disability and sleep problems, the interventions available and the role of parents in seeking help for these difficulties.

1.1.1. Current Context

1.1.1.1. Children and their families

It is estimated there are between 700,000 to 800,000 children under the age of 16 with disabilities in the UK (Contact a Family, 2016; Disabled Living Foundation, 2016). Under the Children's Act 1989 it is a statutory requirement for Local Authorities to hold a register of the number of children with disabilities in their locality. However, registration on this list is voluntary and results in inconsistent and unreliable prevalence figures (Mooney, Owen & Statham, 2008). The variation in prevalence figures can also be attributed to the differences in the definitions and criteria used to describe disabilities, both within and across agencies (Mooney et al., 2008).

Of the estimated population of children with disabilities, figures suggest that 99.1 per cent of them live at home and are supported by their families (Contact a Family, 2016). Research and government policy has increasingly made philosophical and legal shifts to focus on the inclusion of children with disabilities in mainstream schools, encouraging residency at home and service provision in the community (College Report, 2007). This emphasis on families,

and adapting to support children with disabilities represents a shift in how disabilities are understood, from “fixing the individual to fixing the environment” (p. 59, Turnball, Turnball, Poston, Beegle, Blue-Banning et al., 2004). It is argued this has put increasing pressure on families to provide the majority of care for people with disabilities and to make decisions regarding their support (Brown, Schalock & Brown, 2009) and makes assumptions that families both want to assume this augmented level of responsibility and feel capable of doing so (Samuel, Rillotta & Brown, 2012).

1.1.1.2. Policy context

Over the last ten years, a plethora of Government reports (Department of Health, 2001; Prime Ministers Strategy Unit, 2005; HM Treasury & Department for Education and Skills, 2007a; HM Treasury & Department for Education and Skills, 2007b) have indicated that children with disabilities and their families face unique experiences and challenges and are more likely to have poorer outcomes on a range of measures compared with their non-disabled peers; these measures include educational attainment, health and well-being, access to services and employment. As a result policy and research has focused on improving the lives of children living with disabilities, and their families (Mooney, Owen & Statham, 2008). Three priority areas were identified to help improve outcomes: improving access to services and increasing experiences of feeling empowered, having timely and responsive services and enhancing the capacity and effectiveness of services (HM Treasury and Department for Education and Skills, 2007).

1.1.2. Definitions of Disabilities

1.1.2.1. Medical Model of Disabilities

The medical model of disabilities became popular during the nineteenth and twentieth centuries, following the period of Enlightenment (Bury, 2001). It follows linear modernist medical discourses, which separate ‘normal’ from ‘abnormal’ or pathological. The medical model of disabilities asserts that disabilities arise due to biological deficits located in the individual (Fisher & Goodley, 2007). This assertion tends to obscure alternative understandings and

pays little attention to cultural discourses, social oppression or environmental barriers (Shakespeare, 2013). Disability is assumed to be hardwired and there is a focus on rehabilitation and fitting into 'normal' society (Fisher & Goodley, 2007). Within this framework of understanding, emphasis is placed on professional expertise and opinion, which is privileged over the lived experience of those with disabilities (Brisenden, 1986; Fisher & Goodley, 2007)

1.1.2.2. Social Model of Disabilities

The Social Model of Disability (Union of the Physically Impaired Against Segregation (UPIAS), 1976) recognises the impact a person's context can have on their experience of living with a disability; it distinguishes between impairment and disability using the following definitions:

> "*Impairment:* lacking part or all of a limb, or having a defective limb, organism or mechanism of the body;
> *Disability:* the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities."
>
> (Union of the Physically Impaired Against Segregation (UPIAS), 1976)

The Social Model of Disability was born out of a movement, which aimed to shift understandings of disability away from pathological problems located within the individual towards understanding disabilities as a result of the barriers imposed by society in the way that it is constructed by non-disabled people. The movement sought to liberate disabled people and demonstrate that they should have the same rights as non-disabled people and are of equal value despite their differences.

1.1.2.3. Legislative definitions

The United Nations Convention of the Rights of Persons with Disabilities (2006) defines persons with disabilities as:

> “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”
>
> (United Nations, 2006)

Informed by the UN Convention the United Kingdom’s (UK) Equality Act 2010, defines individuals as a person with disabilities if:

> “you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.”
>
> HM Government (2010)

It can be argued that this definition falls within a biomedical paradigm and is reductionist in it’s neglect of the impact of the socio-cultural contexts on a person’s experience of their disability, despite their inclusion in the UN’s definition.

The above are all wide-ranging descriptions and definitions, each with their own strengths and limitations, which encompass a number of varied experiences. For the purpose of this thesis, the construct ‘children with disabilities’ will be used, based on the understanding that the experiences of those children who have long-term physical, mental, intellectual or sensory impairments may be hindered by the barriers imposed by society, and prevent their full or equal access to mainstream social activities. The impairments described here include neurodevelopmental disorders, Learning Disabilities, physical disabilities and sensory impairments, although this list is not exhaustive.

1.1.3. Summary

In light of this shift in policy and the increasing pressure on families, it is perhaps unsurprising that families with children with disabilities experience additional and unique challenges, which can result in psychological distress. It

is helpful that Government policy and funding has recognised these challenges and are seeking to better support this population. However, these are not the only challenges faced by this group. It is to these areas that we now turn and consider the existing literature.

1.2. Literature Review

This section describes a narrative review of the literature related to parenting children with disabilities, sleep problems and seeking help. The review was conducted across the following databases: Academic Search Complete; PsychINFO; CINAHL Plus; Child Development and Adolescent Studies and PsychARTICLES.

The results from the searches can be seen in Table 1 (see Appendix A). The search terms ‘sleep’, ‘relationship to help’ or ‘help seeking’ were used in conjunction with the words defined below. The table illustrates how searches were narrowed by age and subject. No date ranges were implemented, but the search was limited to those written in English. In total there were 281 articles, which were considered to be relevant. Further relevant literature was located through the reference lists in articles of interest.

1.2.1. Terminology

1.2.1.1. Disabilities

In order to encompass the range of definitions, types, constructs and conceptualisations of disabilities the following search terms were used: ‘disabilities’, ‘impairments’ or ‘retardation’. The use of the term ‘disabilities’ in this thesis will refer to all types of disabilities including sensory, physical, learning, psychosocial and neurodevelopmental.

1.2.1.2. Parents

The definition of 'parents' has become increasingly diverse, in today's society any number of persons can be described as a child's parent: biological parent, adopted parent, step-parent, guardian, carer. It is not within the scope of this thesis to discuss the implications of such structural, cultural and linguistic diversity (Samuel, 2007); however, the following search terms were used to encompass this: 'parents', 'carers', 'caregivers', 'family members', 'guardians'. The term 'keeper' was also included as it features in the search terms used on the databases. The term 'parent' will be used throughout this thesis to capture these differences.

1.3. Raising Children with Disabilities

There is a vast body of research which has shown that raising a child with a disability has significant challenges for their caregivers and families (Pisula & Kossakowska, 2010) and can be stressful and disruptive for them (Dyson, 1997). These challenges can include psychological, social and economic burdens, which are said to have detrimental effects on the parent's quality of life and their physical and mental health (Samuel et al., 2012; Isa, Aziz, Rahman, Ibrahim, Ibrahim, Mohamad et al., 2013; Elmore, 2014).

The research suggests families of children with disabilities are more likely to experience difficulties in relationships, more often leading to the breakdown of the parental relationship compared with families with children without disabilities (Department for Work and Pensions (DWP), 2008). Studies have shown that both parents can experience high levels of stress and upheaval (Smith, Oliver & Innocenti, 2001), which may contribute to these relationship difficulties. It is said that parents of children with disabilities also experience feelings of isolation as a result of discrimination and stigma, which impacts negatively on their emotional well-being (Contact a Family, 2011). According to one charity, 52 per cent of families living with a child with disabilities are at risk of experiencing poverty (Contact a Family, 2016). This is likely to be due to costs of additional care, added to the likelihood that the primary caregiver is often forced to give up their employment (Konstantareas, Hornatidis, & Plowright 1992) due to the amount

of time and energy they spend caring for their child with disabilities (Crowe and Florez 2006). In most cases the primary caregiver is the mother (Lee, 2013). The implications of poverty can be far-reaching, including poorer physical health (Wilkinson & Pickett, 2009) and limited ability to access support and resources (Hagan & Smail, 1997).

1.3.1. Common Reasons for Referrals to Services

Services in the UK that offer support for children with disabilities and emotional and behavioural problems, tend to be either specialist, standalone services provided by local health and social care providers, or integrated into local child and adolescent mental health teams (CAMHS). Although children with disabilities may be referred to services for reasons related to some of the parental and familial factors described above, more commonly referrals are made about problems 'within' the child (Beresford, Stuttard, Clarke, Maddison & Beecham, 2012). The two most common referrals to services are for sleep difficulties and challenging behaviour (Beresford et al., 2012)

1.3.1.1. Challenging behaviour

Emerson's (1995) definition of challenging behaviour is the most commonly accepted and cited definition. It says challenging behaviour is:

> "culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities".
>
> Emerson (1995)

The concept of challenging behaviour has been critiqued by some (College Report, 2007; NICE, 2015) who argue it is better thought of as behaviour that challenges others. What is pertinent here is the estimate that rates of behaviours that challenge are three to four times higher in children with

disabilities compared with their non-disabled peers (Baker, McIntyre, Blacher, Crnic, Edelbrook & Low, 2003; Emerson, 2003). For children with disabilities, particularly Learning Disabilities or Autism Spectrum Disorder (Rzepecka, McKenzie, McClure & Murphy, 2011; Beresford et al., 2012), these behaviours tend to include behaviours that are difficult to manage, distressing for the child and others, or interfere with family and school routines (Beresford et al., 2012). They are also a primary reason for placement in residential schools (Abbott, Morris & Ward, 2000), as these behaviours, particularly in children with Learning Disabilities can place considerable stress on the child's family (Rossiter & Sharp, 2001; Baker et al., 2003).

Behaviours that challenge can exist on their own, but are more often underpinned or exacerbated by other difficulties, including sleep problems. Sleep problems have been shown to have a significant impact on the daytime functioning of children (Stores, 2001; Richdale & Baker, 2014), including behavioural disturbances, irritability, drowsiness, attention and learning problems and emotional distress (Sheldon, 2001; Paavonen, Almqvist, Tamminen, Moilanen, Piha, Rasanen & Aronen, 2002; Sadeh, Gruber & Raviv, 2002; Richdale & Baker, 2014). Blum & Carey (1996) suggest that children who experience sleep difficulties are more likely to experience daytime challenging behaviour, when compared with children who do not experience sleep difficulties. In their longitudinal study of 490 children, Gregory and O'Connor (2002) found that sleep problems at age four predicted behavioural and emotional problems in later life, and were equally predictive of anxiety, depression, aggression, and inattention. These results were correlational and so causation is difficult to determine; however, it does suggest sleep problems increase the level of risk for other difficulties.

1.3.1.2. Sleep problems

Research suggests the prevalence and severity of sleep problems is significantly higher in children with disabilities compared to those without disabilities (Wiggs & Stores, 1996; Keenan, Wild, McArthur & Espie, 2007; Chen, Carmichael Olson, Picciano, Starr & Owens, 2012) and compared with age and IQ matched control groups (Patzold, Richdale & Tonge, 1998). Quine

(2001) adopted a quantitative questionnaire approach to a study of over 400 children attending mainstream and 'special' (as described in the study) schools (the latter indicating the presence of a disability). Her findings suggest that sleep problems are common in children with and without disabilities (Quine, 2001), but are significantly greater amongst children who attend special schools compared with their non-disabled peers. Overall prevalence figures for sleep problems in children with disabilities range from 25% to 86% (Wiggs & Stores, 1996; Richdale, Gavidia-Payne, Francis & Cotton, 2000; Didden & Sigafoos, 2001). In a recent review, Tietze, Blankenburg, Hechler, Michel, Koh, Schluter and Zernikow (2012) posit that two thirds of children with developmental disabilities experience sleep problems, and this figure rises to 90% for children with neuro-degenerative disorders. Sleep problems in children with disabilities have been described as the most persistent childhood behaviour difficulties and can last through to adulthood (Bramble, 1997; Mindell, 1997, Robinson & Richdale, 2004). Explanations for these elevated prevalence figures may include ideas that physical and medical conditions can affect children's sleep (for example, sleep apnoea is common in children with a diagnosis of Downs Syndrome), or that parents may have lower expectations for their child's ability to learn new sleep routines, or that communication difficulties make it challenging to convey these instructions (Quine, 1991; Wiggs & Stores, 2004).

Most of the research to date has focused on sleep problems in children with labels of Autism Spectrum Disorder (Richdale & Baker, 2014) and some research suggests that sleep problems are more prevalent in this population (Richdale, 1999; Beresford et al., 2012). Other literature suggests that prevalence rates are consistent across types of disabilities and disorders. For example, Tietze et al. (2012) concluded from their review that presence of a sleep disturbance was not linked to a specific syndrome. In Richdale and Baker's (2014) review of recent literature, they reported that sleep problems are common in individuals with developmental disabilities regardless of age or diagnosis. Possible explanations for these differences include the lack of consensus across studies about the definitions of sleep problems (Richdale & Baker, 2014); there is also the issue that many studies use questionnaires which have not been standardised or have not been validated for use with populations of children with disabilities (Richdale & Baker, 2014).

Although the research regarding prevalence rates and severity in particular groups of children with disabilities appears to be mixed, there is strong evidence suggesting that children with disabilities experience more sleep problems than their peers without disabilities. These findings are important because there are a number of difficulties associated with sleep problems that impact upon children and their families.

1.3.1.3 Types of sleep difficulties

International Classification of Sleep Disorders (ICSD)

Sleep disorders are commonly classified using the ICSD (American Academy of Sleep Medicine, 2001). This system divides sleep disorders into three categories: dyssomnias, parasomnias and sleep disorders associated with other disorders. Dyssomnias include difficulties initiating or maintaining sleep or excessive sleepiness. Parasomnias are sleep problems related to difficulties in the sleep process, for example arousal or difficulties transitioning between sleep stages. Sleep disorders associated with other disorders include those co-morbid with other mental, neurological or medical disorders, such as sleep disturbances associated with experiences of unusual beliefs or anxiety, dementia or fibromyalgia (American Academy of Sleep Medicine, 2001).

Sleep Problems

Studies indicate the majority of children with disabilities experience difficulties with settling to sleep, night waking and co-sleeping (Bartlett, Rooney & Spedding, 1985; Quine, 1991, 2001; Hodge, 2009; Tietze et al., 2012). These difficulties appear to be common across disabilities, including those children with a label of ASD (Richdale, 2001).

However, most children are not given a diagnostic label for their sleep problems, their difficulties are described using the symptoms they experience, for example difficulties with settling to sleep. This is also the case in the literature, where there is limited use of diagnostic labels and an abundance of definitions of sleep problems. The tools used to assess sleep problems also vary and include, physiological assessments, observations and parental questionnaires (Wiggs, 2001). Whilst the use of diagnostic labels has been

critiqued (Timimi, 2014), the lack of consensus in the definitions of sleep difficulties is problematic in terms of its relationship to inconsistent prevalence rates. This could also highlight how sleep problems become subsumed and understood as being an aspect of the disability, resulting in the prevalence of sleep problems being under-reported. However, this is an academic concern, where the real life challenges experienced by children and their families are great and transcend the issue of definition.

1.4. Difficulties associated with Sleep Problems in Children with Disabilities

The literature suggests that poor sleep has a profound impact on and is crucial to children's development (Stores, 2002; Chen et al., 2012). This is largely due to the function of sleep in aiding physical and psychological rehabilitation, conserving energy and growth and development (Stores, 2001). A number of physical and psychological phenomena are therefore associated with, and can be exacerbated by, poor sleep (Doran, Harvey & Horner, 2006).

1.4.1. Physical Health Problems

Sleep difficulties have been associated with a range of health problems for children with disabilities. These include neurocognitive deficits, decreased growth, metabolic alterations, cardiovascular sequelae (Sadeh, Gruber & Raviv, 2002; Chervin, Ruzicka, Giordani, Weatherley, Dillon, Hodges…Guire, 2006; Capdevila, Kheirandish-Gozal, Dayyat & Gozel, 2008) and limited motor skills (Doran et al., 2006).

1.4.2. Behavioural Difficulties

Sleep difficulties have also been indicated in behavioural problems, as described earlier in this review (see section 1.3.1.1). Behavioural problems include attentional and social interaction problems (Goldman, McGrew, Johnson, Richdale, Clemons & Malow, 2011; Taylor, Schreck & Mulick, 2012),

poor school performance, daytime hyperactivity and inattention (Chen et al., 2012). Some research suggests that the severity of the daytime behaviours increases as the severity of the sleep problems increase (Taylor et al., 2012).

1.4.3. Psychological Effects

The psychological effects of sleep problems for children with disabilities include difficulties managing experiences of anxiety, fluctuating moods and emotions, which can be extreme (Sadeh et al., 2002; Chervin et al., 2006; Capdevila et al., 2008; Goldman et al., 2011; Taylor et al., 2012).

It is not altogether surprising to learn that children who experience sleep difficulties and are tired during the day, have difficulties paying attention in school, feel irritable and exhibit behaviours that challenge the boundaries and resources of those around them (Minde, Faucon & Falkner, 1994). What the research does highlight is the need to take sleep problems seriously and ensure children and their families are supported with this (Quine, 2001).

1.4.4 Parental and Familial Well-Being

The literature base suggests that parents of children with disabilities already face a number of challenges (Dyson, 1997; Pisula & Kossakowska, 2010; Samuel et al., 2012; Isa, Aziz, Rahman, Ibrahim, Ibrahim, Mohamad et al., 2013) to which sleep difficulties present further difficulties for them and their families.

1.4.4.1. Parenting stress

Parenting stress is a multi-dimensional construct (Lee, 2013) and has been described as a discrepancy between the demands of being a parent and the personal resources one has, which affects several areas of life (Ostberg, Hagekull, Lindberg & Dannaeus, 2005). Hodges, Hoffman, Sweeney and Riggs (2013) investigated the impact of children's sleep on maternal stress. They examined the sleep of 90 typically developing children and 90 children with a

label of Autistic Spectrum Disorder who ranged from four to 12 years and were matched on age, gender, and ethnicity. The data from standardised questionnaires was analysed; the results suggested that maternal sleep quality was impaired by children's sleep problems, which had led to an increase in maternal stress and reductions in feelings of well-being. This relationship did not differ by the child's developmental status (either children with developmental disabilities or typically developing children), suggesting that sleep problems across the spectrum of child development have an impact. This is of note when considering parents of children with disabilities who are more likely to experience sleep problems when compared to the general population.

The study from Hodges et al. (2013) suggests that poor parental sleep as a result of child sleep problems results in experiences of poor parental mental health and stress. However, it can be argued that parental stress may also contribute to the maintenance of sleep problems in both parent and child, for example where parents experience stress because of chronic sleep deprivation, which can lead to inconsistency in parental care, especially regarding the bedtime routines, thus maintaining the problem (Cox, 1988; Quine, 1991).

1.4.4.2. Depression and anxiety

Indeed Lee's (2013) review of the literature concerning mothers and children with disabilities, showed a bidirectional relationship between poor sleep quality and experiences of depression. In Chu and Richdale's (2009) study, children's sleep scores and children's sleep disturbance were associated with maternal sleep, which was significantly correlated with maternal depression, anxiety and stress intensity and frequency.

1.4.4.3. Attachment and bonding difficulties

Research has also indicated that sleep problems can result in 'disturbed parent-child interactions' (Benoit, Zeanah, Boucher & Minde, 1992). The experiencing of parenting stress (Ostberg et al., 2005) or emotional distress may limit a parent's capacity to provide 'good enough' (Winnicott, 1949) parenting for their children (McLennan & Kotelchuck, 2000; Knitzer, Theberge & Johnson, 2008), and has implications for children's socio-emotional development.

Children who are tired are likely to push boundaries and be challenging for others; parents who are themselves tired and stressed as a result of their child's behaviour are, unsurprisingly, more likely to report irritability with their children and are more likely to rely on styles of parenting that include forms of punishment, they also report using smacking more frequently than parents who do not have children with sleep problems (Quine 1992). Sleep difficulties disrupt whole family life (Morrell, 1999; Cotton & Richdale, 2006) and in some extreme circumstances can be a contributing factor in parenting that is deemed to be abusive (Chavin & Tinson, 1980).

The direction of causality between sleep difficulties in children with disabilities, parental mental health and difficulties in the attachment relationship is not well defined. However, the risks associated with these difficulties are enough to warrant concern and indicate that helping parents seek help around their child's sleep should be a priority for services for children with disabilities.

1.5. Interventions for Sleep Problems

1.5.1. Sleep Services

Services specifically designed to offer support for sleep problems are limited across the UK. There are a number of specialist paediatric sleep services that offer assessment and intervention, but services specifically designed for children with disabilities are rare. Where these services do exist, they tend to be located within children's disability services provided by health and social care; families often have to rely on a referral being made on their behalf by a professional working with them. Otherwise services are located in the third sector, so include charities and private organisations, which may mean parents incur a cost for accessing these services.

1.5.2. Parental Involvement

The far-reaching impacts of sleep problems on children with disabilities and their families (Quine, 1992; Wiggs & Stores, 1996; Stores, 2002; Chen et al., 2012) suggest that interventions directed at improving the well-being of all involved are important for enhancing quality of life, and opportunities for the child living with disabilities (Samuel et al., 2012).

Parental involvement in interventions is cited as a critical component of a successful intervention (McBride, 2009). Since the 1960's there has been a shift in how interventions are provided so that most interventions for children's behaviour now includes parental involvement (Eyberg, Nelson & Boggs, 2008; Beresford et al., 2012). However, Keenan et al.'s (2007) study found that parents can experience these interventions as demanding and time-consuming.

Interventions for children with disabilities and sleep problems typically fall in to two categories: pharmacological interventions and cognitive-behavioural interventions. Pharmacological interventions include melatonin and are the preserve of the medical and psychiatric community (Keenan et al., 2007).

1.5.3. Cognitive-Behavioural Interventions

Cognitive-behavioural interventions include keeping sleep diaries, modifying sleep routines, extinction, positive reinforcement and stimulus fading (Robinson & Richdale, 2004). The underlying principles in these types of interventions assume that children have not learnt appropriate sleep behaviours, and that parental behaviours, such as responding to their child, can reinforce or maintain these behaviours (Mindell & Durand, 1993; Wiggs & France, 2000).

There is a substantial body of evidence that suggests cognitive behavioural interventions for sleep difficulties are effective with children without disabilities (Richman, Douglas, Hunt, Lansdown & Levere, 1985; Hinds, Elliott, & Vettini, 2001; Mindell, Kuhn, Lewin, Meltzer and Sadeh, 2006; Beresford et al., 2012), namely behavioural interventions (Richdale & Wiggs, 2005). In Richman et al.'s (1985) study they quoted an "improvement occurred in 77%" (p.581), which was

linked to those who were able to complete the intervention. Following individualised, child-focused interventions, mothers who had a child with sleeping or feeding difficulties showed a significant reduction in their general stress levels, reported feeling more competent at managing their child's difficulties, and showed more satisfaction in their spousal relationships; child-related problems had also reduced (Ostberg, Hagekull, Lindberg & Dannaeus, 2005).

Beresford et al., (2012) note the lack of research in the UK into how effective these interventions are for children with disabilities. They examined the effectiveness of behavioural parent-training interventions for sleep difficulties for 74 parents of children with disabilities. They concluded that whilst the results are limited because of design and sample size, they do suggest that behavioural interventions for sleep problems are effective for children with disabilities. They recommend that the delivery of behavioural interventions should be continued, but alongside the development of more robust testing of their effectiveness (Beresford, 2009; Beresford et al., 2012). Moreover, research looking at sleep in children with neurodevelopmental disorders recommended behavioural interventions as a first-line treatment (Corkum, Davidson, Tan-MacNeill & Weiss, 2014).

Despite positive results, caution must be applied when considering this research as many studies fail to provide long-term evaluation, and thus the lasting effects of these remain unclear (Richdale, 2013). As mentioned earlier, the research also falls down on a lack of standardization across measures used to assess sleep problems and in terms of its definitions (Hoffman, Sweeney, Gilliam and Lopez-Wagner, 2006). Additionally, the heterogeneous sampling raises questions regarding generalizability of results with some suggesting that interventions need to be tailored to specific disabilities (Khan, Heussler, McGuire, Dakin, Pache, Norris, Cooper & Charles, 2011).

1.5.4. Variability in Interventions Offered and Taken-Up

Although the evidence is limited, it does suggest that cognitive-behavioural interventions can be effective for some parents of children with disabilities and

sleep problems in the UK (Beresford, 2009; Beresford et al., 2012), yet, there is considerable variability in numbers of parents who are seeking help and receiving treatment (Robinson & Richdale, 2004; Polimeni, Richdale & Francis, 2005) and high drop-out rates or difficulties complying with the suggested intervention prevail (Morrell, 1999; Beresford et al., 2012), resulting in high levels of unmet need (Baker et al., 2003). Wiggs and stores (1996) note in their study that 124 parents had answered a questionnaire indicating their child met the criteria for sleep problems based on standardised definitions, but that only 47% of these parents received any help for the difficulties.

Given what is known about the importance of parental involvement in interventions in terms of predicting better outcomes (Morawska, Ramadewi & Saunders, 2014) it seems crucial to understand parents' reasons for seeking help and engaging with services (Didden & Sigafoos, 2001; Polimeni et al., 2005), particularly in the UK context, where individuals are typically referred to services by other professionals. In Morawska et al.'s (2014) interviews with 2999 parents, the results indicated that help-seeking behaviour and parenting style were the only significant predictors of participation in parent-training interventions, when controlling for other variables. This issue seems to be particularly relevant in a context of cuts in funding to the public sector services; resources become over-burdened and stretched, so money and input is only given to the services deemed to demonstrate cost-effectiveness and evidence that they are supporting a number of families (Morrisey-Kane & Prinz, 1999). Further, findings from family support literature suggest that even when interventions are targeted at those considered to be most in need of support, problems with uptake remain (Macdonald & Williamson, 2002).

1.6. Seeking Help

This section provides an overview of the literature pertaining to parental help-seeking, given the active role parents are expected to play in interventions for children and parental influence on help-seeking processes (Morrisey-Kane & Prinz, 1999). Parents may seek help from family, friends and/or professionals. This thesis has discussed the shift towards greater responsibility for parents in

terms of seeking help and making decisions about their child's care. Given the significant decisions parents are expected to make, dilemmas relating to this may be exacerbated by insufficient access to professional help (Sakaguchi and Beppu 2007). The factors influencing seeking help from professionals will therefore be discussed below.

1.6.1. Relationship to Help

Informed by psychoanalytic, systemic and social constructionist theories, Reder and Fredman (1996) developed the concept of a 'relationship to help', meaning the stories, beliefs and attitudes individuals have about help-seeking and help-giving. They assert that clients and professionals each have a relationship to help and it is the coming together of these positions that influences engagement in therapy and outcomes. Although the original article refers to therapeutic situations, the concept of 'relationship to help' can be applied in all settings where someone is seeking help and another is giving help, such as in a sleep service or Children's Disability Team.

An individual's relationship to help is said to be influenced by a number of factors. The authors posit that formative, early attachment relationships provide the foundation for a person's expectations of how another can understand their needs and respond to them appropriately. They also recognise that people live within multiple levels of context and highlight the importance of attending to these influences on a person's relationship to help. For example, the cultural context within which one lives provides them with stories about how to seek help and who gives help. A person's family context influences their perspectives on how difficulties are discussed and the meaning of receiving help. An individual will also hold personal beliefs about help based on their previous experiences with other professionals. Professionals will be influenced by their work context and the assumptions inherent in their professional rules, obligations and duties. Some of these contextual influences will be further discussed below.

1.6.2. Defining the Problem for which Help is sought

Parents may seek help for their child's difficulties, such as sleep problems, because these difficulties are challenging or distressing for others (Miller & Pronz, 2003). In the case of sleep difficulties, Polimeni et al. (2007) assert that children's sleep problems are brought to the attention of professionals when they begin to affect the parental sleep experience, and Quine (2001) suggests parents rarely ask for help until the sleep problem has become chronic and the whole family is experiencing stress and distress. In a study of Cuban mothers of children with ADHD, Arcia & Fernandez (1998) suggest that mothers are "gate-keepers" (p. 333), as they are key in defining problems, which determines how and why they seek help.

Wiggs & Stores (1996) write that "surprisingly few parents" (p. 164) who reported sleep difficulties with their children actually wanted help with the situation. Parental decisions about whether or not to seek help and engage with interventions for a difficulty can be influenced by the parents' attributions about the cause of their child's difficulties (Morrisey-Kane & Prinz, 1999). Reimers, Wacker, Derby and Cooper (1995) assert that parents who define the problem as being biologically determined are less likely to seek environmental interventions on offer, despite their effectiveness, which may contribute to a lack of change for the child and their family and the maintenance of the difficulty. One potential reason many parents choose not to seek help for the sleep difficulties of children with learning disabilities is due to the belief that they are an inevitable consequence of the disability (Robinson & Richdale, 2004; Polimeni et al., 2005), or something that cannot be changed so must be tolerated (Quine, 1991). It may be the case that assigning a biological cause as opposed to an environmental (i.e. parenting style) is associated with less parental blame, for a cohort of parents who might be described as being under considerable strain and stress already (Keenan et al., 2007).

A further explanation relates to the discrepancy between the way that parents and professionals define the problem. The divergence lies in how parents and professionals define the severity of the difficulties, the names and labels assigned to describe them, and how much these difficulties are attended to

(Pavuluri, Luk, & McGee, 1996; Chervin, Archbold, Panahi & Pituch, 2001). The professional definitions are often based on the assumptions of the medical model, which tends to be the dominant discourse in this context (Pilgrim & Rogers, 1997), reflecting a need to meet certain criteria in order for interventions to be offered (for example the ICSD). This may be particularly the case when describing difficulties experienced by children with disabilities, since the concept of disability is so closely tied to the medical model. On the other hand, parents' definitions of the problems tend to be influenced by their subjective experiences of the difficulties (Richdale & Baker, 2014), including the extent to which this impacts on their physical and emotional health.

Defining the problem as biologically determined could lead to diagnostic overshadowing, whereby alternative explanations are masked and overlooked because of the formal label (e.g. Learning Disabilities, ASD) (Keenan et al., 2007). Professionals may not recognise sleep behaviours as problematic until they reach clinical significance and consequently not intervene or discuss these difficulties during assessment. As such, parents may be reluctant to talk about something they identify as problematic because of a lack of awareness or validation from professionals about how distressing these are, and so refrain from seeking help, despite the pervasive effects of their child's sleep problem. This highlights the importance of seeking the perspectives of parents and carers, especially in light of the literature suggesting that concurrence between service-user and professional predicts better outcomes and increased satisfaction with service-delivery (Pilgrim & Rogers, 1997).

1.6.2.1. Failure to identify a problem

Related to how parents define a problem is a failure to recognise that sleep problems exist at all.

In a study of 39 mothers whose children had been matched for sex, age and duration of sleep problem, 18% of mothers did not identify a 'severe' sleep problem when it was assessed by an objective measure, such as a sleep questionnaire giving a Composite Sleep Index Score (Wiggs & Stores, 1998), suggesting that the perceptions of whether or not sleep difficulties were present may influence decisions to seek help (Wiggs & Stores, 1998). The authors

hypothesised that these mothers did not deny the existence of a sleep problem but assert there are protective factors such as perceived control, which enabled them to tolerate the sleep problems and the associated difficulties.

Robinson and Richdale (2004) concluded that what parents consider to be a problem is influenced by more than disturbed sleep in their child or themselves. They analysed responses to a questionnaire on sleep problems and treatment from 149 parents in Australia and found that whilst 60% of children met their criteria for having a sleep problem, many parents did not identify a problem with just half of parents having sought treatment (Robinson & Richdale, 2004). The authors hypothesised that this may have been due to parents' lack of awareness about what constitutes sleep problems, beliefs that sleep problems cannot be treated so should not be viewed as problematic, but an unavoidable part of life, or that there were possible differences in ideas between the researchers and parents about what is 'normal' for a child's sleeping pattern (Robinson & Richdale, 2004). Despite a number of interesting hypotheses, none of these were explored.

1.6.2.2. A problem for whom?

Another argument as to why parents may not recognise a problem and seek-help for their child's sleep difficulties is because their beliefs and values do not fit with the dominant ideas informing how we understand sleep and sleep interventions.

Blunden, Thompson and Dawson (2011) responded to a journal article on sleep interventions by challenging the notion that we need them at all. In their paper they consider the parenting norms in Western society that privilege the elimination of nighttime waking and crying and view it as 'abnormal' or at least unacceptable. The authors argue that pathologising infant communications fits with a neo-liberal hegemony whereby the adult population is encouraged to work, and any barriers to this must be minimised. They call for a critical look at whose needs this parenting practice is serving, is it fulfilling the needs of the infant or the needs of industry giants and capitalism. It is not within the scope of this thesis to further explore this argument, but it does speak to the possibility that not all parents will see nocturnal behaviour as a sleep problem and

highlights the existence of alternative, yet marginalised, explanations that are likely to become obscured or silenced by the powerful voice of the dominant parent-centric view. It is possible that this view is not widespread, and indeed it was quickly countered by the authors of the original paper (Sadeh, Mindell & Owens, 2011). However, what remains important is that research suggests that these difficulties do have consequences for both the child and the parent's well-being, and reasons for seeking help for this still need to be explored.

1.6.3. Help-Seeking Mediated by the Perceived Effectiveness of the Intervention

It seems that when parents of children with disabilities do seek help for sleep problems, they often do so when the associated distress has reached such intensity that they are "desperate" for a solution (p. 187, Morrisey-Kane & Prinz, 1999; Beresford et al., 2012), even if their expectations for change are low (Morrisey-Kane & Prinz, 1999).

However, it seems that certain factors can influence a person's perception of effectiveness and their expectations, and thus, their likelihood of seeking help. In Beresford et al.'s (2010) interviews with parents who had been referred to specific sleep programmes for children with disabilities, they found that if people trusted the referrers they were more likely to take up an intervention and complete it. This concurs with the finding of a parents' survey conducted by Contact a Family (2011) where many of the comments received from parents indicated that they experienced increased anxiety if they believed that their GP did not have the relevant expertise and there was a lack of joint working between agencies, suggesting the parents were reluctant to ask for help. Additionally, positive attitudes towards child mental health services correlate with increased likelihood of seeking help, and the converse is also true, whereby skepticism of services relates to a reduction in willingness to seek help (Diala, Mutaner, Walrath, Nickerson, LaViest & Leaf, 2000; McKay, Pennington, Lynn & McCadam, 2001).

Questionnaires of 58 parents found that the beliefs parents held about the severity of the sleep difficulties influenced the choices they made about

interventions and how acceptable they were to them (Keenan et al., 2007). The study showed that parents found behavioural treatments to be acceptable, but showed a preference for pharmacological interventions if the perceived severity of the sleep difficulty increased.

1.6.4. Help-Seeking Mediated by Environmental Circumstances

The social, cultural and economic contexts within which parents of children with disabilities and sleep problems reside also influence their experiences of and beliefs about help-seeking (Li-Tsang, Yau & Yuen, 2001).

1.6.4.1. Social support

The literature suggests that people are more likely to access formal support if they have a rich network of social support to introduce them to other avenues of support (Barnes, Katz, Korbin & O'Brien, 2006). However, definitions vary in the literature and it is hard to be exact about the composition of useful social networks or what resources are needed (Broadhurst, 2003).

1.6.4.2. Socio-economic status

Parents with a higher socio-economic status tend to seek help more from parenting courses delivered in schools (Cunningham, Boyle, Offord, Racine, Hundert, Secord & McDonald, 2000) and are also more likely to access formal support if they are more affluent (Barnes, Katz, Korbin & O'Brien, 2006) However, this is a simplistic understanding of a complex concept where it may be more useful to consider socio-economic status in the context of social inequalities in health, which may then have an impact on help seeking. For example, low socio-economic status is linked to higher rates of depression, which may reduce motivation and desire to seek help (Spoth, Redmond & Shin, 2000; Wilkinson & Pickett, 2009).

1.6.4.3. Practical barriers

Parents are more likely to seek help if there are fewer barriers to accessing the intervention such as transport, childcare, parking (Kazdin, 2000). Beresford et

al.'s (2012) study included qualitative methods in the form of interviews; they asked participants what encouraged or served as a barrier to their attendance of a parent-training intervention for children's sleep difficulties. The results suggested that parents considered the timing and location of the intervention to be important factors in taking up an intervention. They also showed that parents place more emphasis on how accessing the intervention will affect their lives, compared with the lives of their children, when deciding whether or not to seek help and access support (Rooke, Thomspon & Day, 2004).

1.6.5. Gender Differences in Help-Seeking

Some literature focuses on differences in the help-seeking processes between mothers and fathers. Nadler, Lewinstein & Rahav (1991) posit that fathers of children with Learning Disabilities tend to seek help for instrumental purposes, such as finding active solutions and so the decision to seek help is influenced by the type of 'need-situation'. Mothers help-seeking behaviour was influenced by ego-considerations, they considered the effect of seeking-help on their self-esteem and how others will view their emotional adjustment. This paper concurs with the findings of Jackson's (2011) study which looked at differences in the help-seeking behaviours of 343 male and female undergraduate students, who were asked to make decisions about help-seeking based on scenarios presented to them. The results suggest that men were more likely to suggest working out dilemmas on their own, whereas women were more likely to suggest seeking help from a psychologist. Jackson (2011) argued that this was because men do not recognise emotional or relational problems in the same way as women.

Whilst not directly related to parental help seeking for sleep problems, it does suggest that there are possible gender differences that will influence how people access help and assumes that these differences are 'real'. The cause of these differences is not known and is likely to be influenced by a number of contextual factors (for example a person's culture, family, personal beliefs), and also their relationship to help. An illustration of this is the concept of hegemonic masculinity (Courtenay, 2000) where the notion of a strong man who is not needy or vulnerable (Reder & Fredman, 1996) is privileged in some societies.

Within hegemonic masculinity, the construction of a strong man who is primed for reproduction can be further challenged by the presence of a child with disabilities and additional difficulties, perhaps going some way to explain the potentially reduced likelihood to seek help for fathers of children with disabilities and sleep problems.

Although the literature base appears to acknowledge potential differences between men and women in terms of help-seeking, little is known about fathers' experiences. Phares, Lopez, Fields, Kamboukos and Duhig (2005) caution that the perspectives of fathers are missing from the paediatric psychology literature, or are obscured by the failure to examine paternal effects separately from maternal effects. Indeed much of the research discussed so far in this thesis has described either maternal or parental experiences. In a UK healthcare system that practices according to the evidence base, a body of literature that privileges maternal viewpoints and makes assumptions based on gendered stereotypes that mothers will be the primary caregivers is likely to bias service structures and help-seeking behaviour. The research of Lee (2013) suggests this is the case in most situations, however, failure to attend to the perspectives of fathers and to consider their needs and how they access help is concerning, given what we know about the impacts of sleep problems on parental and family well-being.

1.6.6. Help-Seeking Mediated by Culture

The decision to seek help is likely to be influenced by cultural beliefs about help-seeking (Reder & Fredman, 1996), for example, Ideas that help should be sought within the family, or no one could thrive in life without support from external agencies. Differences between some cultures are often described in terms of individualist and collectivist cultures; although this can be a reductionist approach to considering cultural influences (Tamis-LeMonda, Way, Hughes, Yoshikawa, Kalman & Niwa, 2008) it is helpful for thinking about possible differences. For example, more individualist cultures may subscribe to beliefs that the state should provide help for individuals and that problems are located in individuals (Markus & Kitayama, 1991; Lerner & Ashman, 2006). In cultures more likely to be described as collectivist, there may be ideas that help should

be sought from within the family, extended community and that ‘outsiders’ cannot be trusted to provide help (Markus & Kitayama, 1991; Lerner & Ashman, 2006).

Cultural norms, beliefs and attitudes also shape parental understandings and expectations of children’s sleep. A large study by Sadeh, Mindell and Rivera (2011) looked at how sleep problems are defined in predominantly Asian countries compared to predominantly Caucasian countries. In Asian countries whether or not sleep was defined as problematic was influenced by demographic variables such as child’s age, parent’s age and parent’s level of education. In Caucasian countries sleep behaviours were better predictors of whether or not a problem was reported. Although just one study with its own limitations (exclusive use of quantitative data limiting rich exploration of the contextual factors underlying problem definition and help-seeking), this study is important as it speaks to the differences between cultures, and subgroups within cultures, about how sleep problems are defined, which in turn influences whether or not help is sought.

Furthermore, in a multiple country study, Mindell, Sadeh, Wiegand, How and Goh (2010) asked parents of 29,287 infants and toddlers across predominantly Asian or predominantly Caucasian countries to complete an Internet sleep questionnaire. The results suggested there were substantial cross-cultural differences in sleep behaviours; Asian countries had significantly later bedtimes, shorter total sleep times, increased parental perception of sleep problems, and were more likely to room-share than children from Caucasian countries. The research appears to suggest that cultural differences exist, so it is important to consider what impact they may have on parental help-seeking. As previously mentioned, if parents do not trust that the professionals or service providers have the right knowledge and expertise they are less likely to seek help from them; where there are cultural differences, for example migrant populations, it is possible that parents will not feel understood by professionals and services who are from a different culture and so will avoid seeking help, even if they perceive the existence of a problem.

1.6.7. Stigma

Stigma can be conceptualised as the use of a set of labels, stereotypes and discriminatory behaviors that allow one group to exercise power over another group, lowering their status and subjugating them (Corrigan, 2000; Link & Phelan, 2001). Once other demographic, and cultural variables have been accounted for in parental help-seeking there is still a huge degree of variance, and the authors Dempster, Wildman and Keating (2013) attest that stigma can account for this. Stigma, related to perceived parental burden and threat to well-being, was the strongest predictor of intervention initiation for childhood psychological difficulties (Angold, Messer, Stangl, Farmer, Costello & Burns, 1998) and has adverse impacts on parental quality of life for parents of adults with intellectual disabilities (Chou, Pu, Lee, Lin, and Kroger, 2009).

Felt stigma refers to the experiences of shame and expectation of discrimination that prevents people from seeking help. Perceived felt stigma of the parent will impact upon whether or not the child's problem is discussed with others including professionals (Dempster et al., 2013) and thus is a main mediator of whether or not help for that difficulty is sought. Stigma for parents can mean being viewed as a 'bad parent' and can result in a fear that their child may be treated differently because of society's views about their difficulties and may lead to rejection by peers and other professionals working with them (Williams, 2006). In the study by Dempster et al. (2013) parents were worried about their child being stigmatised because they were seeking help for their difficulties and the possible impact of this upon their child, however, stigma appeared to have a stronger influence on help-seeking when the parents were the potential target for the stigma.

The level of symptom severity also appeared to have an effect on the felt levels of stigma experienced by the parents (Dempster et al., 2013). This is important to note when thinking about children with disabilities and sleep difficulties and the effects that sleep difficulties can have on other behaviours that are perceived as challenging by others. It is possible that parents view these challenging behaviours as more severe and more open to public scrutiny and stigma, therefore seek help for sleep problems to alleviate these behaviours.

1.6.8. The Role of Society's Constructions and Myths in Help-Seeking

1.6.8.1. Perfect parents

According to Pavuluri et al. (1996), many parents do not seek support or interventions for their child's behaviour problems because they believe they should be able to 'fix' their child on their own. This may link to research which indicates that parents have less confidence in their parenting abilities if they perceive children to have significant behaviour problems (Miller & Prinz, 2003). This implied sense of autonomy and independence corresponds with cultural values in individualist societies, which privilege these over inter-dependence, which is commonly associated with more collectivist cultures (Markus & Kitayama, 1991; Lerner & Ashman, 2006). Whilst this distinction is quite simplistic, research suggests that parenting approaches are influenced by these values (Tamis-LeMonda, Way, Hughes, Yoshikawa, Kalman & Niwa, 2008).

Research also suggests that parents may be reluctant to seek help because of beliefs that sleep difficulties are the result of poor parenting practices (Bramble, 1996) or call into question their parenting competence (Morrell, 1999) and they may feel under surveillance and 'policed' by professionals (Peckover, 2002; Fisher & Goodley, 2007). They may fear being labeled as a 'bad parent'; this self-blame may not be functional for parents already under considerable stress (Keenan et al., 2007; Paster, Brandwein & Walsh, 2009). These parents may experience difficulties balancing normal parenting tasks alongside additional physical duties and emotional adjustment, necessitating exceptional caregiving (Dyson, 1997; Lee, 2013). These increased expectations indicate it may be difficult to prioritise seeking help for sleep difficulties in the context of many other demands.

This constructed notion of a 'perfect parent' may be particularly problematic for mothers since the concept of the 'ideal mother' is pervasive in society also. The myth of the 'ideal mother' is one who is caring, loving, self-sacrificing and who acts for others, especially children (Thurer, 1995; Williams, 2006). She is expected to produce a 'perfect child' despite this notion being irrational and

unrealistic (Williams, 2006) and failure to do so indicates weakness in the mother and results in self-blame (Thurer, 1995). These expressions of self-blame have been replicated in studies of mothers of children with disabilities (Todd & Jones, 2003; Rogers, 2005). The mothers in Todd and Jones' (2003) study described feeling as though their "worth and character as mothers were being continually scrutinized" (p.229) in their encounters with professionals, possibly because of the notion that they are responsible for their child's well-being and behaviour, and therefore a child with a disability and sleep problem indicates fault (Williams, 2006). This may act as a barrier to seeking help, especially when the sleep difficulty was impacting upon them, because of fear of being judged, but also fear of being perceived as selfish and thus, undermining their role as advocates if they give voice to their own needs.

1.6.8.2. Children as cherubs

In many Western societies childhood is construed as a time of innocence and vulnerability (Williams, 2006), which positions children as blameless, incompetent and dependent (Sorin, 2005). This construction exacerbates the idea that parents must look after them and adds to the experiences of self-blame, guilt and shame if children fail to conform to society's expectations of the 'perfect child' (Sorin, 2005). Seemingly a consequence of this could be an avoidance of seeking help for their child's sleep problems because of fear of public condemnation, shame and perhaps even ridicule (Sorin, 2005)

Furthermore, there is a persistent desire to achieve a myth of bodily perfection (Stone, 1995; Williams, 2006). In many Western societies this encapsulates a body that is idealized and free from impairment, disorder and deformity (Stone, 1995; Taleporos & McCabe, 2002). Many parents experience stigma because their children do not comply with these 'perfect' images; however, it may also be true that parents of children who have invisible difficulties, such as a sleep problem, may be reluctant to seek help for fear of drawing attention to their child's difference, and the resulting implications of this. The way in which society ignores and discriminates against differences (Stone, 1995, Martz, 2001; Taleporos &McCabe, 2002) is oppressive in its nature and contributes to the marginalization of people with disabilities.

1.7. Summary of the Literature and Rationale for the study

There is considerable literature concerning the high prevalence rates of sleep difficulties in children with disabilities and how these have an impact on the emotional and physical well being of the child, their parents and their families. There are a number of interventions that can be offered to parents to support them in making changes in relation to sleep difficulties. However, there is an alarming amount of variation in the numbers of people who are offered services, and in those who actually take them up.

Much of the research has sought to explore why parents do not seek help, yet low engagement rates prevail. Within this research the quantitative paradigm has dominated. The use of statistical techniques to portion out the relative influences of various circumstantial or structural factors fails to give much detail about what it is like to be a parent of a child with disabilities seeking help for the child's sleep problem. This study seeks to explore reasons why parents do seek help and what influences this process to see if others can also be encouraged to seek help. It will consider how parents establish that there is a difficulty, how they understand or talk about the sleep difficulties, how it comes to be that people are offered services or ask for support, it will also explore the role of others in this process so as to understand problems as being constructed in relation to other people, and the impact of social constructions. These questions will be considered in the UK context where parents often have to wait for professionals to refer them on to services once the difficulties have been brought to their attention.

Given the economic costs of the difficulties associated with sleep problems (Montgomery, Stores & Wiggs, 2004) it is desirable to ensure services can intervene early and provide timely and effective interventions that parents perceive as useful and want to access (Wiggs & Stores, 1996; Robinson &

Richdale, 2004). Considering that parental help-seeking is one of the biggest predictors of participation in parent-training interventions (Morawska et al., 2014) this points to the need to gain further understandings about the complex process of help-seeking in parents of children with disabilities and sleep problems (Broadhurst, 2003). This thesis seeks to do this by attending to help-seeking and by grounding parents' accounts in a framework that attends to the cultural and socio-political processes. It is hoped that an enhanced understanding of these experiences and processes may help to improve children and families' wellbeing since sleep underpins a number of other difficulties. It may also aid in the design and implementation of services to make them more efficient and accessible.

The author's interest in this topic stems from their experience working in NHS services with children who have disabilities and their families; this will be further discussed in section 2.1.2 where the author reflects upon their positioning.

1.8. Research Questions

This thesis aims to attend to the following research questions:

- Does parenting a child with disabilities and sleep problems have any influence on experiences of parenting and help-seeking?

- How do parents of children with disabilities and sleep problems identify and talk about problems with sleep?

- What are the reasons parents of children with disabilities and sleep problems seek-help and engage with sleep interventions?

2. METHODOLOGY

This chapter describes the research approach adopted in the present study and how data was collected and analysed. The research questions identified are exploratory in nature and concerned with understanding the experiences and perspectives of participants located in context; a qualitative approach to data collection and analysis was therefore used. Semi-structured interviews were used for data collection and the method of analysis employed was Thematic Analysis (TA).

2.1. Epistemology and Research Position

Qualitative research can be carried out from a number of theoretical positions. In accordance with guidelines of good research practice (Elliott, Fischer & Rennie, 1999) it is important to be transparent about which stance is being adopted and the possibilities and limitations of such a stance.

2.1.1. Epistemological Stance

The study adopts a critical realist position, as informed by proponents such as Pilgrim and Bentall (1999). This position assumes there is an objective reality but that access to it is mediated by social processes, which are contextually, culturally and historically bound (Willig, 2013) and do not map directly onto people's experiences of reality. Critical realism places emphasis on understanding people's versions of reality through the concepts they use to describe it (Pilgrim & Bentall, 1999). This position makes assumptions that the way in which parents talk about disabilities, sleep problems and the resulting effects are socially constructed and will organise parents' experiences. This research provides an interpretation of parents' versions of reality and the underlying structures that influence them, to offer a richer account of their experiences.

A critical realist position was adopted as it is in accordance with the type of information the research questions seek to find out about; it does not take the data about individual perspectives at face value, but seeks to add meaning through the researcher's interpretations (Willig, 2013). This stance also bears most resemblance to the world-view of the author, which has been strongly influenced by my training in critical approaches to Clinical Psychology, for example narrative therapy and community psychology. These approaches offer a critique of the objective truth-seeking of traditional methods of research and highlight the importance of reflexivity in producing research that can never be truly objective, but is better when the subjectivity of the participants and the researcher is acknowledged (Braun & Clarke, 2013).

2.1.2. Statement of Position in Research

Further to the theoretical orientation of the author, their personal experiences, values, assumptions and beliefs will also shape how they connect with the literature and their reading and interpretation of the data (Clarke & Braun, 2013). Transparency and reflexivity about pre-existing relationships with the subject matter are therefore pertinent to the credibility of the research (Willig, 2013).

With this in mind, there are a number of contexts of note here. Firstly, my interest in this area has developed from my experiences of working in Child and Adolescent Mental Health Services and Neuro-Developmental Teams (NDT); within these roles I have worked with children with disabilities, namely those with physical disabilities or diagnoses of Autism Spectrum Disorder and their families. Through my work in this context I noticed the difficulties these children had in terms of sleep, and the consequential effects for their functioning during the day, as well as the effects on their parents. Within this setting, there was not access to a specialist sleep service and interventions were provided by the NDT; however, resources were limited in this team and there was a pressure on completing assessments over interventions. This meant the help available to families struggling with their child's sleep problem was limited. Through this, I became interested in how parents can be supported to promote better sleep in their children and what services are available to them. Further reading on this

subject highlighted the lack of specialist sleep services for children with disabilities, as well as high dropout rates. I am also invested in early intervention and prevention and I am interested in developing services that can support parents quickly and effectively before problems, and their effects, become great.

Within these contexts, I was also struck by the number of different professionals and agencies that can be involved with families with children who have disabilities, and how they are expected to manage many demands, such as providing care, advocating for their child and attending numerous appointments. Unsurprisingly this was a challenge for some of the parents and I became interested in the expectations and demands placed on parents and how they navigate services.

Secondly, I am not a parent myself; my values about parenting come from my family of origin. In this context of loving, skilled parents, I have developed ideas that parents are helpful, supportive and available. I have developed assumptions from my parental and familial relationships that help seeking and help giving is important. This may have shaped this research as it is interested in facilitating parents to seek help in order to support their children, and assumes that this will be worthwhile.

Finally, I do not have a disability, nor would I consider myself to have a sleep problem, yet through training and my discussions in my work with families, I have heard about experiences of inequalities and prejudices about these issues; for example children being reduced to a label of ‘naughty’ without consideration of any contextual factors, resulting in feelings of blame, shame and lack of opportunities at school. I am aware of dominant, privileged narratives and am keen to increase the consideration of alternative perspectives.

I take the position that sleep problems and the effects are real for parents, and are something that can be shifted with, early, intervention, thus improving the experiences and outcomes for families.

Acknowledging these positions is important to enhance the validity of the data (Ahern, 1999; Elliott et al., 1999), however, this reflexivity is not sufficient on its own. An ongoing consideration of these issues is necessary as the influence of these contexts may change during the course of this research and others that may shape the research may become apparent. Therefore, I will further address this issue and reflect upon it in the discussion.

2.1.3. Research Setting

Specialist sleep services for children and adults are found within the NHS. However, sleep services specifically designed for children with disabilities are not as widely accessible. As this study was specifically considering help-seeking for the sleep problems of children with disabilities, it seemed important to recruit participants who had access to this type of service rather than generic Child Learning Disabilities Teams or support groups, to explore the reasons for seeking help for these specific difficulties. Therefore, the participants were all recruited from the same sleep service, located in an inner-London borough. The researcher was familiar with this service from their time working in Neuro-Developmental Teams, and through conversations with the lead Clinical Psychologist, was aware of the challenges the sleep service were facing with regards to their drop-out rates from interventions. Given that this service was experiencing similar challenges in engagement to those described in the literature and the specialist nature of the service, it was decided this would be an appropriate site for recruitment for this study to explore help-seeking processes.

The sleep service sits within an integrated service for children with disabilities who live in the borough, meaning that health and social care jointly provide support to children from birth to 18 years. The sleep service consists of a Psychiatrist, Clinical Psychologist and Sleep Counsellors; it offers assessments and interventions for sleep problems. The types of interventions include sleep workshops for parents, individual sessions for parents and family sessions, all of which are based on a behavioural model; the medical team also prescribes medication.

2.2. Participants

2.2.1. Inclusion Criteria

Parent: Parent is defined as the child's mother, father, legally appointed guardian or a person with a residence order concerning the child (i.e. those with parental responsibility) (https://www.gov.uk/parental-rights-responsibilities/what-is-parental-responsibility). Participants must have been the parent of a child aged18 years or under, who has disabilities and sleep problems. The parent must have been in contact with a sleep service for children with disabilities.

Disabilities: as defined by the criteria for an integrated service for children with disabilities (see below). The disabilities included were:

- Learning disabilities
- Physical disabilities
- Visual impairments
- Hearing impairments
- Speech and language impairments
- Chronic ill-health
- Autism Spectrum Disorder

This is a loose and broad label. However, given that children with all types of disabilities can experience sleep difficulties, it was appropriate to use this definition.

Sleep difficulties: as defined by the criteria for the sleep service (see below), it included mild to severe dyssomnias and parasomnias.

2.3. Procedure

2.3.1. Recruitment

All parents who had been referred to the sleep service and met the inclusion criteria received a letter informing them about the study; the letter was posted by the sleep service and had been co-signed by the researcher and Manager of the sleep service. The letter asked the parents to make contact with the researcher if they were interested in participating. The researcher contacted interested parties with more information and to arrange an interview where there was a decision to participate. The study aimed to recruit between eight and 12 participants; the sample size was informed by guidance from Guest, Bunce & Johnson (2006) on sample sizes and data saturation. The study also aimed to recruit parents who had engaged with interventions and those who had not engaged with them, to explore different perspectives on the experience of seeking help.

2.3.2. Description of the Sample

In total ten parents were interviewed, all of who had engaged with interventions at a sleep service. The table below (table 2) provides details about the participants and their children with disabilities and sleep problems (all have been assigned pseudonyms).

Table 2
Participant demographic information

Parent's Name	Gender	Age	Ethnicity	Role	Parenting Relationship	Child's Name	Gender	Age	Disability	Sleep Problems
Edie	F	47	Israeli	Mother	Married, main caregiver	Michael	M	10	ASD, LD, ADHD	Night waking
Karen	F	46	White British	Mother	Married, main caregiver	Kyle	M	13	ASD	Settling to sleep, co-sleeping
Saafiah	F	37	Bangladeshi	Mother	Married, joint caregiver	Najm	F	7	ASD, LD	Co-sleeping, Early morning waking
Marilyn	F	36	White British	Mother	Separated, co-parent	Jessica	F	4	Cerebral Palsy	Settling to sleep
David	M	40	White British	Father	Separated, co-parent	Jessica	F	4	Cerebral Palsy	Settling to sleep
Amal	F	47	Moroccan	Mother	Married, main caregiver	Asif	M	18	ASD	Night waking
Sara	F	53	Australian	Mother	Married, main caregiver	Daniel	M	11	ASD, ADHD	Settling to sleep
Izra	F	41	Indian	Mother	Married, main caregiver	Daksh	M	11	ASD	Settling to sleep, co-sleeping
Renee	F	44	White European	Mother	Married, main caregiver	Coralie	F	7	Williams Syndrome	Settling to sleep, co-sleeping
Martin	M	39	White British	Father	Married, main caregiver	Kit	M	5	ASD	Settling to sleep, night waking

Eight of the parents had attended a sleep workshop, five had received individual interventions and two had also received family interventions.

Seven out of the ten participants did not directly seek help for sleep problems from a sleep service. These parents were offered help because they were already in contact with services for children with disabilities, that had a sleep service embedded within the organisation, and professionals had noticed the difficulties they were experiencing and referred them on the sleep service.

2.3.3. Data Collection and Analysis

2.3.3.1. Interviews

Semi-structured interviews, lasting 35 to 60 minutes were conducted. Eight of the interviews were individual; in one instance the parent couple asked to be interviewed together, so this was facilitated. Interviews were held at the premises of the sleep service or at parents' homes (where risk assessment policies where followed). These were audio-recorded and transcribed verbatim without non-linguistic features. Interviews were considered the most appropriate method for data collection because they allowed for the exploration of the complexities of subjective experiences (Willig, 2013).

2.3.3.2. Development of the interview schedule

The interview schedule was largely influenced by the pertinent issues identified in the literature review (such as parents' difficulties noticing sleep problems in children with disabilities) and the subsequent research questions; two main areas of questioning were therefore identified:

- What is it like to be a parent of a child with disabilities and sleep problems?
- What are the experiences of identifying sleep problems and seeking help for these?

Within these broad areas, it was important to ask a question about how parents conceptualised and understood their child's sleep difficulties. This was due to variations in the children's disabilities and sleep problems, alongside intersections with other differences (such as culture, gender) (Crenshaw, 2012), which allowed for differences in the way that these are constructed to be explored.

The interview schedule was then presented to the clinicians at the sleep service as part of a presentation about the study, but no changes followed these discussions. Carrying out the interviews was the final stage of development; as the interviews were semi-structured in nature it allowed for flexibility in terms of

what was discussed, so that the researcher could respond to the participants feedback and follow-up on topics that were salient to the participant, but had not previously been considered by the researcher, meaning that the focus was not constrained.

2.3.3.3. Analysis

The data was analysed using Thematic Analysis (TA) informed by Braun & Clarke's (2006) six-phase guide. TA was chosen because it has theoretical flexibility (Braun & Clarke, 2006; Clarke & Braun, 2013; Willig, 2013), which allows it to sit with a critical realist position. Additionally, TA allows one to make interpretations about the sociocultural contexts and structural conditions that shape the individuals accounts of their experiences, whilst remaining close to the lived experience.

Given this focus on the individual's experience and use of interviews, it could be argued that Interpretative Phenomenological Analysis (IPA) or Grounded Theory (GT) (Glaser & Straus, 1967) was a more appropriate method of analysis. The reasons TA was favoured are documented below:

- Both IPA and GT are better thought of as theoretically bound frameworks or methodologies (Braun & Clarke, 2015) whereas TA is inherently flexible (Willig, 2013) so can be "underpinned by phenomenology as well as a number of other theories" (I'm not sure whether to use IPA or thematic analysis – what's the difference? section, para. 3. Braun & Clarke, 2015).
- In IPA the primary focus is on personal, idiographic experience (Smith, Flowers & Larkin, 2009), whereas TA is primarily focused with patterns of meaning across participants; thus, making it more appropriate for the present study which also aims to address the wider systems and contexts that surround an individual's experience.
- TA was chosen over GT as it is not attempting to develop a theory, but to explore experiences and socio-cultural processes which mediate these (Braun & Clarke, 2015).

An inductive approach to TA was used, whereby the themes identified were driven by the data and strongly linked to it (Braun & Clarke, 2006; Patton, 2015). The data was coded and interpreted independently from pre-existing theoretical frames. However, one cannot claim that it was purely inductive as the active identification of themes was inherently informed by the earlier review of the literature and their own experiences, beliefs and assumptions (Taylor & Ussher, 2001). In this way, the approach partially adopted a deductive approach also. This is in accordance with the idea that themes do not 'emerge' from the data, rather are actively constructed by the researcher (Taylor & Ussher, 2001) and are not a direct representation of the actual conversation (Bannister et al, 2011).

2.3.3.4. Stages of analysis

The analysis was informed by Braun and Clarke's (2006) six-phase model of TA, although this is not a prescriptive methodology and as such was used as a guide.

- Phase one: Familiarisation with the data began with the transcription of the interviews and the reading and re-reading of them. A list of interesting points and ideas about the data was generated.
- Phase two: This phase involved assigning codes to extracts of the data that were relevant to the research questions; the codes were at the semantic and latent levels of analysis (Braun & Clarke, 2006). Latent level analysis was facilitated by the use of the researcher's reflective diary, where accounts of each interview were kept to make note of features such as strong emotional responses, hesitations or changing views across interviews. A table of codes and related data extracts from across the interviews was generated (see Appendix C), which helped to get a sense of the broad issues.
- Phase three: The codes were then organised into related themes or subthemes based on any central or unifying features or patterns across the data set; this involved cutting them out, moving them around and clustering related codes around one another, or in proximity to each other where there were any similarities. This generated a set of initial

candidate themes (see Appendix D), which captured the most salient patterns in the data.

- Phase four: The candidate themes were then reviewed and refined (see Appendix E) by considering if there was enough meaningful data to support them. This was important to achieve a sense of coherence within a particular theme, but also across the interviews. Data extracts and codes were checked back against the themes to ensure they were covered and formed a coherent pattern. The themes were then reviewed against the interviews to ensure they were an accurate representation of the meanings in the interviews.
- Phase five: This phase happened in conjunction with phase four, as the essence of each theme was determined and how well the extracts fit was reviewed. The narrative process of writing-up the analysis and defining themes saw a further reviewing of the themes and data extracts, and a refining of the boundaries of the themes as they were organised into a coherent story.

To further validate the themes, the participants were offered the opportunity to comment on the themes and subthemes constructed from the data. The themes and a brief description of them were emailed or sent by post to participants. One participant responded to this offer; they said:

> "Although I can relate to most of the themes I think that the one which I can relate the most is the 5th one.
>
> One point that might be missing is concerns for the future. While in some cases parents adapt and find ways to cope with the sleeping problems, the future is a great concern since we do not know how long we will be able to carry on and how will this problem reshape when child reaches adolescence"

Whilst this is an interesting point, it does not feature in the results chapter as it was not shared across the interviews.

2.4. Resources

The study required an interview schedule (Appendix F), audio-recording and transcribing equipment, password-protected laptop, encrypted USB device and the use of a room at the sleep service.

Remuneration was not offered

2.5. Ethical Considerations

The considerations outlined below were carried out in line with guidelines from the British Psychological Society's (BPS) Code of Ethics and Conduct (BPS, 2009).

2.5.1. Informed Consent and Protection of Participants

Participants received an information sheet (see Appendix H) and were asked to sign a consent form (see Appendix I) prior to commencing the interview. They were also reminded of the limits to confidentiality, their right to withdraw from the study and that they did not have to disclose participation to any other parties. After the interviews were completed the participants were offered a short debrief. If any concerns were raised or any participants became distressed when talking about their experiences and challenges they faced, they were signposted to the Clinical Psychologist at the sleep service. Information on the local Patient Advice and Liaison Service (PALS) was given to all participants.

2.5.2. Confidentiality and Anonymity

All participants and persons named in the interviews were assigned pseudonyms for the process of transcription, to protect their identities. The researcher was the only person to hear the audio-recordings and these will be destroyed after the study has been favourably assessed. Information relating to the study, including audio-recordings, is stored electronically in an encrypted file on the researcher's password-protected computer and on an encrypted USB.

2.5.3. Ethical Approval

Ethical approval was granted by the UEL Research Ethics Committee (see Appendix K). NHS Research and Ethics Committee London – Central ethical approval and Central North West London Foundation Trust Research and Development approval was also granted (see Appendix L and M) for recruitment from the sleep service.

3. RESULTS

In total five themes were constructed from the analysis (see table 3 below); in this chapter each theme will be explored and illustrated using extracts from the interviews. Although the themes represent commonalities across the data set, the degree to which they represent meaning in all, some or most of the interviews will be acknowledged to highlight the nuances of the findings and the subjectivity of the data.

Table 3

Themes and Subthemes constructed from the data.

Themes	Subthemes
1. Identifying Sleep as a Problem	Difficulties in identifying sleep as a problem associated with disabilities Picking your battles It becomes a way of life
2. How to do Parenting	Doing the right thing or being a bad parent Taking responsibility
3. Escalation of the Sleep Problems: Eliciting a Help-Seeking Response	Feeling overwhelmed Feeling powerless The disruption of individual and family life
4. Can you get Help for Sleep Problems?	
5. The Context of Parenting a Child with Disabilities	The emotional impact of having a child with disabilities Sharing with others Visible versus invisible differences

3.1. Theme One: Identifying Sleep as a Problem

Parents described challenges in identifying sleep problems as a key issue for them, either because they were in the context of other difficulties that take priority or the sleep problems could be understood in alternative ways.

3.1.1. Difficulties in Identifying Sleep as a Problem associated with Disabilities

When parents started to become concerned about their child's sleep they did not associate this with their child's disability. Parents were keen to have an explanation for the problematic sleep, but used other frameworks to understand it, for example explaining sleep problems through a psychological lens. For others, they were keen to understand whether or not the sleep was 'normal', whether or not it was a problem with them or a problem with their child

3.1.1.1. Having an alternative explanation

Marilyn said "I don't think I ever saw it as a SEN[1] thing" (Marilyn, 405) and instead conceptualised it as her and her partner's lack of experience and confidence:

> And she's our first child, and you know, we were a little bit like, what do we do, (Marilyn, 460 - 461)

Martin said he had not considered the link between disabilities and sleep problems and believed this was something professionals should share with parents:

> You know, you almost need a dummies guide saying are you having sleep troubles this is what you should do, because there's nothing out there, what I have seen (Martin, 601 – 603)

For Amal, she was perplexed as to why the sleep problems had increased when it was something they had been dealing with for a long time; she attributed this to child development and growth, and her own lack of control over this:

> Maybe because he is growing and it is difficult now to control him,

[1] SEN is an acronym used in the UK for Special Educational Needs and can be synonymous with 'children with disabilities'.

> because maybe when he was small, you know it is easy to control and erm, small children they get tired and they sleep, but when they get more bigger, more energy and especially he is not doing nothing…Or something happened, some hormone change in his body or something happened, because he was last, I mean the last two years he is very bad (Amal, 209 – 220)

An explanation rooted in psychological distress seemed to fit best for Sara as she described not seeking help for the sleep problem because she understood it to be caused by her son's experiences of anxiety:

> So yeah, it was really difficult and that's when his sleeping style, pattern, problems started. I don't know whether it was, I thought it was anxiety about school, so I didn't really get help, [I: Right] Because I always thought that was it (Sara, 73 – 78)

This was a similar experience to Karen:

> Well really from the beginning I never really noticed a problem because we all slept in one room… erm, that's when I noticed about his sleep, but I thought it was because we always shared a room and then he's suddenly gone in with his little brother (Karen, 20 – 28)

This ability to mentalise their child's emotions and to consider what might be causing them distress is perceived by some as a valuable parenting skill, and one that is venerated in society as a way to 'do parenting'. However it seems that accepting one explanation for sleep problems is in itself problematic as Karen and Sara made attempts to help alleviate their child's distress, yet the problems remained, and so the effects of the sleep difficulties did too:

> I thought, you know, he was frightened of going there, and it would have settled down but it just didn't, and then I was like sleeping with him for, forever, it felt like forever (Karen, 55 – 57)

This dominant narrative may have acted as a barrier to alternative causes being explored, and thus, alternative forms of help being sought.

3.1.1.2. What is normal?

For Izra, there seemed to be an experience whereby professionals also failed to acknowledge alternative explanations and were informed by prevailing narratives on parenting practices and ideas about what is 'normal' for babies. This speaks to the idea that professionals hold some expertise over best practice and that this power can influence what parents feel able to do for their children. Izra describes the strong sense of knowing her child well, yet still adhering to professional power and not feeling validated as a result:

> You know as a parent, even of a parent of a first child, first born, he's my first born, you know you know that there is something wrong, you know, I knew it right from the beginning [I: Okay] But I, so which is why I went to my paediatrician in Singapore, and uhm, he just didn't really take it that seriously (Izra, 206 – 213)… oh just put him into a sleep routine, just massage him, do this, do that, I mean of course you should do all that, but if you try for a month, or month two months whatever, if it doesn't work you need to take that more seriously (Izra, 219 – 222)

For Saafia the ideas about how babies should behave were salient:

> Sleep difficulties, until she was four because, until she was four she used to sleep with me and I thought okay she was baby, we treat her like a baby so expected (358 – 360)

The dominant ideas that babies should behave in a certain way and one should only become concerned when they veer from this norm organised Saafia's understanding of the sleep difficulties. She was not concerned as she had explanations such as she cries at night because her nappy needs changing; whilst this may be true, the absence of an individualised approach to children

meant in this instance that difficulties were not identified until her daughter was six years old and her behaviour was compared to that of her younger brother:

> A six year old should sleep all through the night, because if my baby can sleep all through the night, a two year old can sleep all through the night, why not her. (Saafia, 379 – 382)

For Iris, some of her concerns were minimised by those around her as they were seen through the lens of “boys will be boys” (Iris, 195) meaning they expected him to be active and energetic and her concerns about this were unfounded because it is how boys ‘should’ be. This meant that Iris had to contain her concerns and manage them; she commented that it was not until her son was given a diagnosis of ASD that she felt able to “justify” (Iris, 197) his behaviour and her concerns, as the label ‘allowed’ him to be different.

This was a similar experience for Sara:

> Before Daniel got diagnosed that everyone kept, a lot of people would say he's fine, all boys do that, all boys never listen, all boys are fidgety, all boys are, oh he's fine and that used to really get me down because I knew he wasn't, and even now they still dismiss that (Sara, 361 – 366)

The limitations of viewing children’s behaviours through these constructed lenses of gender are that these parents were not given the permission to fully express their concern and approach relevant professionals for their support. For both Sara and Iris, the diagnosis came later, and the help for sleep problems later still, meaning they were coping with a great deal of distress for both themselves and their children.

3.1.2. Picking your Battles

For some parents the existence of a sleep problem was not as much of a concern for them because they were experiencing other challenges:

> And actually I want to pick my battles and not sweat the small stuff, and you know there are bigger fish to and all of that (Marilyn, 157 – 159)

This extract from Marilyn suggests that the sleep problems were seen as minor and insignificant when compared to other challenges that she had to face such as promoting her daughter's physical health. Iris noticed that she could not remember asking "them that loudly" (Iris, 300) for support with sleep problems. This was echoed by Renee who said:

> So as a parent it's painful. You can't fight, I can't fight for everything, I have to give priority to what is important, otherwise it would be difficult [I: You would be fighting all of the time?] Yeah, and it would be exhausting and would put people to not really like you (Renee 437 – 443)

The idea that there are constant challenges for parents of children with disabilities seems to have organised their understanding of how much difficulty is to be tolerated, and suggests that these parents will need to 'put up' with a certain amount before considering the idea of seeking help or involvement from others. It may be that parents are pre-occupied with understanding the underlying causes of their child's disabilities and difficulties, through the acquisition of a diagnosis for example, which means that other concerns have to move down the list of priorities:

> I knew there was always something wrong with Kyle and it was me trying to push push push, I didn't pay much attention about the sleep to be honest, but it's just his other things that I knew he just weren't right and his learning weren't right (Karen, 217 – 221)…it was that, but I didn't pay much attention to the sleep bit (Karen, 227 – 228)

It seems that these parents were seeking a medical response to what they saw as the problem (disability), against which sleep was seen as secondary. This

may have organised parents' intentions for seeking help through an implicit hierarchy of difficulties and need:

> For us, it was like let's save the boy, and try to make, the first thing he needs to learn, he needs to be able to cope in this world when he is awake, so I guess for us it was, when this will fall into you know, we make progress there, then will probably affect his sleep somehow. Because you know, you have the top three and then I guess sleeping was number five. (Iris, 300 – 307)

For Iris and Karen there also seemed to be a lack of understanding about the consequences sleep difficulties can have on children's other areas of functioning. The privileging of finding a solution to the challenges resulting from the disability meant that the effects of sleep problems on attention, learning and concentration were minimised:

> It's (sleep) a physical thing, we can deal with that [I: Okay] Rather than cognitive or intellectual thing, it wasn't the main (concern) (Iris, 309 – 312)

> But I weren't really interested in the sleep thing then, I just wanted the help Kyle needed at school, I weren't really bothered (Karen, 260 – 263)

3.1.3. It becomes a Way of Life

The challenge in differentiating the sleep problems from other concerns, and seeking help for them, seems to have been exacerbated for these parents through the way in which the sleep problem and resulting implications had become a familiar way of life, when Amal was asked when she first noticed the sleep problems she said: "they was always issue was there" (Amal, 208). Others had similar responses, suggesting the sleep problems became normal:

> I think they have been going on forever. (Iris, 99)

> I think we all just got so used to it and that was it, you know because at one stage I didn't think nothing, I used to think oh god it's just another night, and I used to dread the nights, but it was something I'd done for so long, so (Karen, 395 – 398)

> But you know sometimes because of the routine, if you don't really realize (Renee, 214 – 215).

It's interesting that implicit in these ideas about routine and sameness, is the idea that sleep behaviours cannot change:

> For a long time it was just a way of life, I was just thought that's it and that's what we've got to do (Karen, 110 – 111)

The lack of awareness of services that can help facilitate these changes will be discussed in theme four, but it is also worth considering again the dominance here of the biological understanding of disabilities and it's assumptions that symptoms, behaviours and impairments cannot be changed but need to be managed and tolerated:

> In the beginning I thought oh this isn't too bad. In the sense that you think, I suppose I felt like what is the other alternative? (Martin, 239 – 241)

Although not explicitly commented on by the parents, it is notable how many of them saw the sleep problem as something that had to be simply endured:

> Which it wasn't but those thoughts come into mind, you're left with well it's going to be an issue forever, but actually it wasn't in the end (Sara, 477 – 480)

3.2. Theme Two: How to do Parenting

3.2.1. Doing the Right Thing or being a Bad Parent

The notion of being a 'perfect parent' seemed to organise the way in which parents understood their role in alleviating the sleep problems and the distress for their children. The 'perfect parent' intuitively knows how and is able to reduce any distress or suffering their child is experiencing:

> Part of me thought I'm doing all that, I'm doing all that so what am I doing wrong still, and still does this mean this is it? (Sara, 475 – 477)

> As a parent, as a father I've got to protect my children and I don't know what I'm supposed to protect him with (Martin, 446 – 448)

In spite of the unrealistic nature of this construction, parents described feeling as though they had failed and experienced "guilt" (Sara, 139) for not being able to provide this, which was a distressing process for them:

> I think that to me is probably the hardest thing with the Autism, the lack of sleep and all of that, is the feeling of hopelessness and helplessness. It's a feeling like I can't do anything, I can't help him, I can't help him go to sleep, I can't help him because I can't understand sometimes (Martin, 448 – 453)

This failure appeared to undermine their parenting skills and abilities; they were not able to find a solution for the difficulties, which meant the problem lay with them, and they blamed themselves as a result, which was very distressing for them:

> It's very frustrating obviously, because you tend to blame yourself, [I: Yeah?] Yeah, bad parenting (Iris, 180 – 183)

> Iz: it was very hard, it was very hard, it was I've broken down so many

> times, I cried a lot, I was never in denial really but I had the other stages of you know grief, I did grieve a lot, first of all it is like why did this happen to my child, what did I do wrong, when toward everything that I did from pregnancy, from the time that I got pregnant till he was born, I thought you know I used to play a lot on the mobile phone at that time because you know in Japan mobile phones are a big thing
> I: Yeah
> Iz: And I'm like oh maybe I shouldn't have played on the mobile phone, maybe that did it, I used to stay up at night and do that, that's why he stays up at night, you know things like that, all everything passes through your mind, oh I should have done that right, I should have done that right. (Izra, 675 – 691)

These beliefs appeared to act as a barrier to seeking help for these parents, for fear of being judged as a bad parent. However, when they did eventually receive help, these beliefs continued to impact upon their relationships with services. For some discussing their concerns with professionals seemed to be useful because it helped to normalise their experiences and help them feel they were not the only ones going through this:

> It was good to, yeah, feel like you're not alone or a crap parent (Sara, 309- 310)

Whereas for others, they seemed to perceive judgment from professionals. Karen felt as though professionals were “picking on you and making you upset” (Karen, 641) because the sessions were individual ones for her; this perceived judgment may have been in part due to the individual sessions tapping into Karen’s experiences of not being able to help her son herself, meaning that the problem was with her. For Renee, the presence of so many services and professionals in her life appeared to undermine her abilities as a mother to take care of her child herself:

> After when it was better I stopped seeing the psychologist because, and as well she left she was a lovely lady, but it was enough and I didn’t want it to add more therapy, more me going to any hospital or anything.

> For me, the less we can go the better it is (Renee, 191 – 196)

Parents or professionals were not the only ones to uphold the ideal of a parent who is able to provide exceptional care at all times. Martin was concerned what judgments his neighbours would make about his parenting abilities if they heard that his son was awake and they were not able to get him to sleep:

> We would you know be worried about the neighbours, so we trying to keep quiet (Martin, 108 – 109)

Izra experienced much more explicit judgment from her peers whereby their values about how to be a parent where informed by these 'perfect parent' constructions and so they held her experiences up to them and judged her to be failing as she was not able to 'fix' her child:

> I think I happened to mention it, I was like you know he has issues, I didn't mention that he was not sleeping till 12…so I was like he doesn't sleep you know, and I was like branded as the worst mum, who couldn't really take care of the child and wasn't doing the right things for the child, and there was like 10 mums gave me advice on what I should do, how I should do…so yeah, I was kind of branded as the worst mum (Izra, 401 – 417)…And then I just zipped (my mouth) and I said you know what, I'm not discussing this [I: Yeah, because how did that feel for you?] Not nice, not nice, very isolating, very very isolating (Izra, 419 – 422)

Providing comfort and relief from sleep problems was not the only parenting task to be done and Amal noticed that trying to make things better in terms of the sleep problem meant she was less able to manage some of the other tasks she needed to do; this too feeds into the idea of not living up to perfect parenting standards whereby you are expected to be able to do it all and cope with it:

> Because when I don't sleep in the day I have to wake, to cook, shopping, cleaning and you do the housework (Amal, 128 – 130)…It was hard for me because I have to leave so many things to give him time for him, (Amal, 143- 144)

The sleep problem itself elicited responses in some parents that were not in accordance with their views about how they wanted to parent their children, and this influenced their decisions to seek additional support. For example, Martin felt so tested by the sleep difficulties that he considered using physical punishment:

> It's funny like smacking children is something that is quite common in South Africa but its not something that I've ever done or want to do, but I can almost, its that type of thing where you can almost see why people do it because you have no control you just feel like I can't deal with this, I'm just going to, which makes no sense at all, I'm going to smack you because I can't cope with it, but that's it, I can see, there were plenty of times where I thought just give him a smack, but its not going to solve anything (Martin, 574 – 583)

Izra spoke of the challenges in dividing your attention between all of your children and how unfair it seemed to her daughter who did not have a sleep problem or disability:

> She wanted me to be with her all the time, she's, she's a mumma's girl and she always wants me to sleep with her, so she was sleeping with us, and she just, every every night there was a squabble over mum slept with you yesterday so today she has to sleep with me (Izra, 551 – 556)

This seemed to resonate for Karen too, and she spoke about not spending as much time with her other son as he "just gets on with things" (Karen, 464) and the sadness she felt abut this, possibly because this was not the model of parenting she had in mind for him, but it was determined by the needs of her

son with disabilities and sleep problems:

> You know Mark has probably suffered the most because all my attention always been on Kyle not on him, because he hasn't got the problems and the needs, I didn't pay him as much attention, probably still don't to be fair, I think he's just got used to it, which is a bit sad (Karen, 443 – 448)

3.2.2. Taking Responsibility

Connected to beliefs about being a perfect parent was the idea that they must take responsibility for parenting their children. This premise is foregrounded by the context of a shift away from collectivist societies where there is a focus on inter-dependence towards an increasing trend of individualism in developed, Western societies. This seems to have influenced how parents understand who takes responsibility for the tasks of parenting and who is accountable:

> Obviously it's not an easy thing, but at the end of the day you are parents and you have responsibilities and duties so (Iris, 413 – 415)

> Because it's my child and at the end of the day I have to look after her, she's my responsibility (Saafia, 702 – 704)

> But you know, I was like a terminator, you just have to, just human beings like women we don't complain. I'm just a tough cookie, and I'm responsible so I just did what needs to be done. (Renee, 375 – 378)

Descriptions of being like a "terminator" suggest that whilst there is some status to be had by being responsible for your children in this way, it is also hard work which requires 'superhuman' strength.

These parents' experiences also speak to a Western, individualist understanding of distress, whereby the problem and solution are assumed to exist within the individual:

> Because what we do, I feel, that's our belief, I should never ever depend on others. I can get help, I can seek for help from all the professionals, but I don't always close my eyes and say okay I'm just going to wait for what them to tell me what exactly to do (Saafia, 698 – 702)

> I mean you have to approach people, the thing is if you sit at home and twiddle your thumbs then nothing will happen, you have to, I mean go to the right people and there will be hits and misses (Izra, 906 – 909)

It seems that these understandings influenced how parents responded to the process of seeking help; they assumed responsibility for 'fixing' the difficulties and made attempts to address them before seeking help, and even when they did seek help they made attempts to remain an active participant in the process:

> You don't straight away phone them, I was waiting a bit to see if it was on a regular basis or something accidental. It happened that it was getting more and more. So I sent her another email (Renee, 117 – 120)

For Sara, it seemed that it was not sufficient to just be offered explanations and interventions from professionals, she felt as though she needed to contribute also:

> But after talking with people and doing a little bit of our own research, you know, we thought we'd try it. (Sara, 288 – 290)

Another interesting aspect of this notion of responsibility was that for some parents what they found most useful when they did seek help was not a 'cure' for their child's sleep difficulties. It was the experience of being offered reassurance that they were doing enough to help their child and permission to be 'good enough', meaning that they were allowed to make mistakes, not be 'perfect', and seek support; for example Karen spoke of being told by a Clinical Psychologist about another family in a similar situation, where the mother had stopped offering exceptional levels of care and did what was good enough.

Karen said this helped her to take a position of “that's it I'm not doing no more” (Karen, 281 – 282), which meant that she no longer had to lie with her son every night and was able to sleep in her own bed. Sara also noticed this:

> When you put a child to sleep and you know you say it's time for sleep now and that’s it, you've given them so much (Sara, 219 – 221)…But this is how I've interpreted it and how it made me feel better, is that you've given everything all day you don't have to continue it, when its time for sleep its time for sleep and actually its important that they go to sleep. (Sara, 223 – 227)

A striking feature of this responsibility was that it was mostly assumed by just one parent in the parent couple; seven out of ten participants reported being the main caregivers for their child with disabilities and sleep problems:

> I wouldn't say it was shared, it's still mainly me because I just think that's what the routine he's used to so that's what I do (Karen, 302 – 304)

> I mean, we are trying, sorry, but my husband used to and still travels a lot so I can’t really tell that he’s always there to do, to share (Iris, 391 – 393)

> I mean it's hard because even my husband, he is old man, and he's ill, he's diabetic, blood pressure, and he has his own business, he has to be from morning until 9 o'clock or 10 o'clock in the evening, yeah, so it's, it's really hard (Amal, 185 – 189)

> I don’t delegate a lot because I do a lot with her, he leaves early, he comes back, as you can see, late. Coralie, her day is already, she came back from school we did her homework, bath, food, sleeping, reading and all the thing (Renee, 634 – 638)

It seems that this division in care giving was not solely driven by stereotypical gender roles, as Martin took on the main caring duties and Marilyn and David

shared the responsibility between them. However, it was mainly mothers who took on this role, whilst their partner tended to provide financial support.

The parent who provided the main care for their child, also assumed decision-making responsibilities. It seems that the decision to seek help for sleep problems was often taken by the main caregiver when they reached a point where it felt unbearable to them.

Sara described the moment where she took the decision to seek help:

> Yeah, my decision, but erm, Emily [Clinical Psychologist] said that he could always come back at another time if he [husband] wanted to (Sara, 207 – 208)

In this quote, Sara is talking about how it was her decision, but the Clinical Psychologist involved ensured that the invitation for intervention was open to her husband as well; however, Sara said that her husband never took this invitation up.

Renee describes the moment when she said to herself, and to her husband that she could not take any more and needed extra help to manage the sleep problem:

> And I said enough, enough is enough (Renee, 90)

This appeared to be a similar experience for Karen, although she said she did not talk to anyone about it first:

> I didn't even ask them, I just went ahead and done it because I couldn't cope with it no more (Karen, 401 – 402)

These two quotes demonstrate the strain a child's sleep problem can put on a parent, and a family, and that one parent alone often assumes sole responsibility. Given what was talked about above in terms of parents'

motivations to tolerate a lot of strain and distress before they seek help, it is important to consider how this impacts on one person and how they cope with it:

> You know you can't help but feel sometimes that if she was tired, completely legitimately, because you are tired anyway, looking after Kit even if you have a good night sleep you're tired (Martin, 349 – 352)… so you can't help but think, come on I'm tired what do you mean you're tired, at least you had some sleep I didn't have any sleep and I'm tired (Martin, 356 – 358)

> Because I was at home most of the time, it's hard for you to take your mind off and you are with your child most of the time, so if you are at home and if you are always there, you're at it, it kind of drains you, it's psychologically very draining, and isolating, I've used this word many many times, but yes it is isolating (Izra, 710 – 716)

> As a mother, as a parent, I would say. I mean for my husband at least he had his work, I wouldn't say it was a great thing but he had, he had to use his brain differently, but for me there was no escape, there is still no escape (Izra, 718 – 721)

Saafia was unique in her experiences of sharing responsibility with her husband:

> So we never had this problem like I'm doing alone and you're not, no we're always shared and he, he was very happy with that and we felt it's fair (Saafia, 632 – 634)

Saafia and her husband were not in employment at the time the interview was conducted and so were able to share day and night caring duties as no one had to fulfill employment duties during the day, as well as equally sharing financial responsibilities. Interestingly Saafia reported the least impact on her life, her family's life and the least amount of distress; this may be due in part, to the fact it did not feel like a burden for one person but it was shared and there seemed

to be an understanding that we are doing the best we can. Saafia was also the only parent who reported providing more help than seeking it and seemed to be the most comfortable with the process of seeking help.

3.3. Theme Three: Escalation of the Sleep Problems: Eliciting a Help-Seeking Response

The impact of the sleep problem on the parents was a particularly salient context when it came to understanding what informed their decisions to seek help for the difficulties. These can be categorised into three broad areas of experiences: feeling overwhelmed, feeling powerless and disruption to individual and family life.

3.3.1. Feeling Overwhelmed

Parents appeared to be more inclined to share their difficulties with professionals when the sleep problems and the impact they were having began to overwhelm them, physically and emotionally:

> And I was exhausted, I was exhausted. I couldn't understand why when I'm feeling exhausted, the feeling of being unplugged, really and truly, literally (Renee, 381 – 383)

There seemed to be many experiences where the parents attempted to tolerate the difficulties for as long as possible, but eventually sought help:

> But you know, we reached a point where we couldn't really cope with that. And yeah, I guess that was that (Iris, 108 – 109)

Parents noticed the sleep difficulties were impeding on their abilities to do things that were important to them. For example, Iris felt unable to fulfill herself because of the impact of the sleep problems:

> I think again, its like down to the basic, what do I need to do to get through this day. [I: Yeah] And minimise the expectations, and then, I think the other end of it is the frustration of not being able to fulfill yourself. (Iris, 405 – 410)

Fulfilling oneself can include feeling well, feeling supported, doing activities that you enjoy:

> I think the reason why I went to that workshop is probably because I think we'd had a period where Jessie was just refusing to go to bed and kept coming here and I'm an [...] student so I study in the evenings and it was being really really disruptive to my studies, to my mental well-being and to my need to be able to watch Corrie to relax (Marilyn, 170 – 176)

It seems that this inability to fulfill yourself impacted upon parents' wellbeing, their sense of self and worth. For Martin, the situation became so difficult that he questioned how much longer he could go on like this:

> But it got to the stage where I just realised I don't know if I can actually keep going like this, I just can't physically do this anymore, just can't, I need some sleep. And uhm, I mean it was really like torture. It was absolutely, it was the most difficult period of my life I would say besides finding out he was autistic (Martin, 264 – 269)

> It just got to the stage where life just was not even worth it. I was so tired and so, and it had really an adverse effect, I was so tired and angry (Martin, 250 – 252)

This speaks to the notion that these parenting responsibilities were totally overwhelming and affected other areas of their lives, which were paid little or no attention. It seems this was difficult for these parents as they were denied the opportunity to live their other identities, such as someone who is capable, creative or funny, and were restricted to an identity full of struggle, distress and stress. Iris found that she could be herself more when she was out of the family system and not being viewed through the lens of a parent of a child with disabilities and sleep problems:

> I find it easy because it's not there, and it's not present. (Iris, 466 – 467)

Renee and Iris felt that the late nights spent trying to get their child to sleep and not being able to leave them on their own left them feeling overwhelmed and constrained by the sleep problem:

> I, you have to acknowledge that, it becomes first priority, it is ruling your life in a way. (Iris, 437 – 438)

Renee described "really a feeling of a prisoner" (Renee, 227) implying a sense of feeling trapped by the sleep problem:

> It's a feeling of being completely trapped. For her, like she took over me, which is not what it should be [I: Yeah] She dictated to me what I should do, and I had to sleep. Sometimes I was drained, and sometimes I fell asleep, I remember even me I had to hide and read a book (Renee, 207 – 213)

> Well, it, we realize we are human and you do need your sleep. Its something you think, like people in captivity and people like that and you know that you lose your personality and you know you lose your way of seeing things, of being capable to handle things because tiredness takes over everything. (Iris, 397 – 402)

This sense of being trapped and taken over is a difficult experience for a group of parents who are already experiencing considerable strain and it may exacerbate any other pressure they are feeling, hence making decisions to seek additional support.

3.3.2. Feeling Powerless

The impact of the sleep problems seemed to be perceived as difficult when they challenged the ideas that adults are supposedly in charge and are the more powerful individuals in the parent-child relationship.

> My mum always says never let the child rule the adult. (Marilyn, 590)

> And you know actually he was feeding off wanting me. He was the one controlling me to come, keep coming and actually probably kept him awake because he knew I was coming back (Sara, 237 – 240)

It is possible that these experiences were particularly difficult for these parents as they may already be feeling 'done to' and powerless because of the experiences of having a child with disabilities. This additional attack upon their status may have been too much for them to bear, and so they made decisions to seek help:

> That's why I sought therapy. She was not going to decide what I was going to do, I'm the mother, I'm the one who should lead and help her and not take me being dictated by a three/four year old little girl. (Renee, 220 – 224)

> As I said I can't just, because of her diagnosis everybody cannot change our lifestyle, we have to do the things what we need to do with her (Saafia, 776 – 778)

> And now I find myself going, it's a bit of a mantra, I will not let the child rule me (Marilyn, 600 – 601)

3.3.3. The Disruption of Individual and Family Life

Amal described living in a situation with a child with disabilities and sleep problems as:

> Madness! (Laughter). Yes, it's madness [I: Okay] Because you're already having very hard time without sleep problems. If the sleep problems comes in the top that means it's madness. It's really and, you cannot keep with that. (Amal, 194 – 199)

Another influence on whether or not support was sought was when parents noticed that their child was not able to do 'normal' things expected of them:

> I think when he (husband) started realising that Daksh was really struggling with sleep and we couldn't put him in to, you know when he was school going and we couldn't put him into you know, morning normal school because of the sleep issues, I think that's when he started realising we needed to do something about it (Izra, 621 – 627)

This may have been a particularly organising feature of seeking help as it may have highlighted difference between their child and others that the parents hoped to minimise, given the way difference is experienced by individuals. It may also have been painful for parents to realise this, and so this emotional distress prompted them to seek help for it.

The sleep problem also had an effect on their relationships with their partners:

> Yeah frustrating, and it used to get us down, and it obviously put tension between us because you know we would just sit down to have your evening and you know he would be back again (Sara, 133 - 136)

For some of the parents, sleeping with their child meant they were not sleeping with their partners during the night and Karen noticed that this had an effect on the physical side of their relationship as well as the emotional aspect:

> Well with my husband, obviously we didn't share a bedroom so that part weren't very good (Karen, 439 – 440)

Whilst these were not choices the parents had made, there did appear to be more of a willingness to tolerate some of these difficulties compared to impacts on their sense of self for example. Martin noticed the sleep problem not only affected his personal relationships, but also his professional ones, and talked of an almost resigned response to this:

> I just thought this is what my life is going to be like. You don't think there is any, you can't think, I couldn't think outside of the box, uhm, I was struggling with work, you struggle in your personal relationships, your professional relationships, I mean it had such a knock on effect for us (Martin, 337 – 342)

However, it seems that parents were more inclined to seek help when they noticed the impact the sleep problem was having on their other children:

> But is has big impact on my other two, because she is having sleep difficulty my nine year old child who is not been able to sleep and then she screams (Saafia, 237 – 239)

It was "really hard" (Amal, 310) for Amal's daughter who was disturbed by her brother during the night, this left Amal feeling distressed:

> Yeah, I was upset. I was very upset with that. But erm, at the end of the day I say it's my son what can I do. It wasn't easy, it was very difficult. I'm still now it's not easy, it's not easy now at all" (Amal, 353 – 356)

Amal received letters from her daughter's school complaining about her daughter's lack of concentration which may have left Amal feeling judged about her parenting (as discussed in an earlier theme) and so added to the impetus to seek help.

3.4. Theme Four: Can you get Help for Sleep Problems?

Seven out of the ten participants did not directly seek help for sleep problems from a sleep service because they either did not know you could name it as a problem, or they did not know services specifically designed to offer help for sleep problems existed. These parents were offered help because they were already in contact with services for children with disabilities, that had a sleep service embedded within the organisation. This meant that whilst most of them had eventually noticed the sleep problems and did want help to reduce the frequency and impact of them, this was not something they asked for from services.

> I was just like casually, I was just talking to, I was just saying and then she thought maybe I need some help (Saafia, 452 – 454)

For Saafia, it felt like the sleep difficulties were something that she mentioned in passing, and which professionals picked up on and suggested they could help with; she reported finding this an easy process, suggesting that the attunement of professionals and their knowledge in the area was valuable.

Even when professionals pointed out a link between disabilities and sleep problems, Sara was still unaware that you could get help for this:

> Well actually I didn't think, well they said it can go hand-in-hand and I thought yeah that's what it is, but I didn't think then, oh you can get help for this. It wasn't until they told me [I: Right] That you can get help. (Sara, 177 – 182)

Martin was meeting with professionals to consider aspects of diagnosis and disabilities and in these sessions he described how tired he was because of the sleep difficulties his son was having, and it was only due to this that the professionals suggested he attended the sleep service:

> If we didn't have the option I don't know where we would be now. Having had the options with Laura we were able to get the help that we needed. I don't know how we would have got help otherwise to be honest. (Martin, 610 – 614)

Parents may feel a sense of embarking into the unknown when their child is given a label of disability, because this was not what they expected parenting to be like. This context could explain why some parents may rely on professionals, and indeed need them, to guide them towards support and advice:

> It's very hard for parents, very hard, it's hard because I think first of all you know, parenting children, parenting children doesn't come with a you know manual, parenting children with disabilities is harder because there isn't any rule, there isn't any rule, so you have to find your own way, and it's hard to find your own way. (Izra, 321 – 327)

Only one participant described asking directly for support regarding the sleep problem. For others, they were attending appointments at partner agencies, and it was these professionals who suggested they be referred to the sleep service:

> I suppose when we started going to see the lady in CAMHS, and we just talked everything through and then she said you need to work because of your, your being so tired and I mean obviously it's not helping Kyle, so that's how I knew that way that, because I just thought it was him, that he needed something, not that it was a problem with his sleep. (Karen, 231 – 237)

> I actually, I can't even remember who I spoke to, because it was quite a lot involved, erm, I think, erm, one of the CAMHS, her name is Saraya, its the CAMHS, because I got to see her not because of the sleep problem, I used to see her for something else… And then like I mentioned to her about the sleep difficulty, and we having, and she referred (Saafia, 424 – 437)

One reason participants gave for not seeking help specifically for sleep problems, once they had identified that this was a problem and something they would like to be different, was because they were not aware these services existed or what they could offer:

> It was a bit like when I first started coming here, I used to think oh god this is just such a load of rubbish you know, and it's not going to help (Karen, 258 – 260)

> I wouldn't question that we can actually get help for these types of things, which I think is really important for other parents to know, yeah, I don't think there is enough information about there to say you can get help. Or enough information to say with Autism you often get sleep difficulties (Sara, 376 – 381)

This suggests Sara did not know that services exist to help people in these positions, and so it is unsurprising that she felt unable to seek help for this problem. Sara made this point clear when she said:

> But these can be addressed, solutions, that is the sort of information, that's the information that I would have liked. (Sara, 383 – 385)

Iris said that when her son first received a diagnosis of ASD she was told about sleep problems, but that it was done in such a way it was difficult for her to retain this information and use in the future when she did identify sleep problems:

> In a way, it felt like you know the experts we met at that time, they had ticked the box and said, hey we've informed them about that (Iris, 203 – 205*).*

Being assigned a diagnosis can be a turbulent and emotional time for parents, and so plying them with lots of information may not be appropriate as there is already too much for them to process; Martin said he had been hit with a "bombshell" (Martin, 270) indicating the enormity of the experience of his son being given the label of ASD.

This experience of information, about the link between disabilities and sleep problems and sleep services, not being accessible to parents and their families addresses some limitations of the healthcare system. It seems to suggest that in order to access help parents have to rely on professionals to provide them with information, and that you can only access this help once you are in contact with services. This position seems to make assumptions that parents are both motivated and able to access them in this way, and assumes they have the resources to be able to do this. Martin recognised this assumption in his experiences:

> I can read the language, I can write the language, its my first language and I couldn't find any help, so when it's not your first language how do you find any help, I don't know. (Martin, 622 – 625)

It may also suggest that stories about disabilities limit people's perceptions and expectations of what can change.

3.4.1. Experience of Receiving Help for Sleep Problems

Whether help for sleep problems was asked for by parents or recommended by professionals, the overall experience of receiving help was positive. Renee found the support timely, pragmatic and "brilliant" (Renee, 507) and based on

these experiences felt confident that if she were to need help again in the future she would be able to ask for it and would find it useful:

> If one day I encounter another difficulty I know she's here and I will be inclined to send her an email. (Renee, 518 – 520)

For others, they did have positive experiences of seeking-help but wished for it to be more individualised or for the process to be made shorter. Karen found that she had to see her GP, then be referred to a hospital before being referred to a sleep service and said the process took over a year in total which left her feeling "disappointed" (Karen, 364). In addition to this, the process of changing sleep behaviours and seeing improvements does not happen immediately and for some parents this was difficult to accept as they had been living with it for such a long time and were now reaching the threshold of their tolerance. Karen's advice to others was to "persevere" (Karen, 654) and then you will see changes:

> Well obviously it has now, but I suppose back then if you'd asked me going through it, I used to walk out of here thinking, I used to tell Emily [Clinical Psychologist] this anyway, but I used to walk out of here thinking well it's such a waste of time, you know, this lot are just wasting my time here, every, every other Monday, Monday was it, yeah I think it was every other Monday, used to come here, it would be such a long time and I used to go out here thinking that's that I'm not coming back, but I used to come back luckily and then yeah, obviously in the end, when something does happen and you think oh thank god you know (Karen, 608 – 618)

Martin described feeling "a little bit abandoned" (Martin, 588) when solutions were not found at once, which can be understood in the context of the desperation he was feeling at the time, indicating that a lot of pressure and expectation was placed on services to deliver changes right away. This is not realistic and can be used to explain why some parents may not continue with intervention plans when results are not instantaneous.

By the time these parents received help for their sleep problem, it seemed that they had reached a point where the impact on them and their families was great, and they were in a position of really wanting help. It is perhaps unsurprising then, that many of them said by this point they took the stance of:

> There is help on hand and you know, we need to make the most of it. (Iris, 383 – 384)

This position seems to have been facilitated by some of the parents' perspectives on help seeking. For example Marilyn said:

> I thought well that could be useful, erm, I mean I'm one of these people who will think oh, I'll go on anything that's available that might be useful (Marilyn, 411 – 413)

For Izra, this view on help seeking was influenced by her experiences in other countries where she had to pay for services; she spoke of how valuable she found the free NHS services and the remit of them:

> I think, just whatever help you can get, just take it, that's it, if it's there just take it, you know, and be grateful for it, don't complain (Izra, 966 – 968)

This willingness to receive help may be influenced by an over-riding wish to satisfy physical and emotional needs, and to simply have some sleep for both the parent and the child:

> But at the end of the day as long as she goes to sleep, it's a win (Marilyn, 272 – 273)

3.5. Theme Five: The Context of Parenting a Child with Disabilities

This theme addresses the challenges that parents of children with disabilities face, and offers a context to frame the processes of seeking help for sleep problems. In spite of the wealth of literature and policy addressing the challenges parents and families of children with disabilities face and the changes in practice, this context was still highly salient for these parents and did not seem to suggest there has been much change in terms of society's conceptualisations of disabilities, resulting in feelings of anger, loss and difference for these parents. This broader context of parenting a child with disabilities relates to some of the earlier themes such as the difficulties parents have in identifying sleep problems and dilemmas about being able to help your child; thus, sleep problems can be viewed as one element of this broader context.

3.5.1. The Emotional Impact of having a Child with Disabilities

One particular area was the profound emotional impact parenting a child with disabilities had on them; the experiences these parents described resonated with experiences of loss, grief, sadness and anger. Renee described it as challenging "emotionally and as well socially" (Renee, 262):

> I mean to be parents for child with special needs, it is not easy at all, you have no life, no life at all. You cannot go nowhere, you cannot even have rest, you cannot even have sleep, and especially if you don't have help, like me I don't have help, no help at all (Amal, 178 – 183)

> I don't think there's enough acknowledgement for parents, how hard it is, and I think if more people, if more parents spoke out and said it's hard and it hurt, (Sara, 486 – 489)

This context is important when thinking about seeking help as these parents appear to be describing experiences of additional distress and upheaval that

need to be expressed, explored and processed. Martin described meeting with professionals for this purpose:

> We, just basically for some extra support, because both my wife and I really struggled with the diagnosis [I: Okay] And there were tonnes of anger issues, that I was experiencing at the time. Not in any way directed towards, although, not to Kit (Martin, 149 – 155)

It is possible that these extra demands have to take priority over thinking about other areas of difficulty, such as sleep problems, which would also go some way to explain why parents have difficulties identifying sleep problems. It is conceivable that the sleep problems and associated difficulties do not receive intervention, which increases the stress on these families.

A position of "internal conflict" (Martin, 196) was also described whereby parents understand and are aware of advice and suggestions from professionals to help with their experiences, but the emotional response to having a child with disabilities hinders being able to do this:

> I think that its one of those things where you struggle as well because its so difficult being a parent of a disabled child, and then you know these things that you should be doing, and then people say well you shouldn't really do that because that's the problem. But you think it's hard enough with him as it is, I don't want to make his life any harder (Martin, 189 – 195)

Sara spoke about already feeling as though she was doing so much, and that extra demands were beyond what she was prepared to do:

> And I didn't do it in the end but, to be honest it was a selfish reason, it was the thought that I'd have to take this blanket everywhere we went [I: Yes] And that's, I felt terrible for saying that because if it helps him I should do that, but I just didn't want another piece of something (Sara, 322 – 328)

Two of the parents described parenting a child with disabilities as living in a parallel world, highlighting how different it feels to have a child with disabilities and the different trajectory you are expected to take; implying also that you have to learn new ways of parenting:

> There is a point you realize, you know you've started at maybe a similar starting point, but they children go here, and you're in a completely parallel universe, it is so different (Iris, 452 – 455)

> Because you, you know it's like the mathematical definition of two parallel lines, you know they face each other but they never meet (Renee, 250 – 252)

3.5.2. Sharing with Others

This context also seemed to inform how much parents shared with others and were able to seek support from them. It seems that parents avoided sharing their difficulties, including sleep problems, with others as it highlighted the differences between their child and children without disabilities or sleep problems and in some cultures was seen as "taboo" (Izra, 240). They were also concerned about how it meant they were viewed as a parent. It is possible that this suppressing of experiences and emotions may have built up for parents to a point where professional help was the only viable option due to the frequency and severity of the problem.

Karen described her experiences when she tried to speak to her family about her son's sleep problems:

> So to my sisters, I think they think I talk a load of rubbish, they don't understand (Karen, 498 – 499)

When Iris was asked about how she talked to others about the challenges she experienced, she said “to be honest it is not something I am sharing with other people” (Iris, 447 – 448); Iris went on to explain “otherwise you’re just drawn into this condition” (Iris, 460 – 461) and:

> I guess, what I would like to do with friends is to remember that a part from being a parent for a disabled child, I‘m also other things, so there’s an opportunity for me to, I guess discuss to other topics” (Iris, 455 – 458)

Renee said she did not share her difficulties with her friends as she felt they would be unable to help her, or would not understand because their children were not having similar difficulties:

> No because I was, not really, not really I mean, people, my friends had children at the same time, yes some people, say my friends, you know her son, she left the hospital straight away and did 12 hours of sleep. And the other thing, I was so much, another thing with her and her condition, erm, that people couldn’t do anything for you. Nobody would have said okay I’ll come for a night and you go and you sleep (Renee, 357 – 364)

For Amal, talking to others in similar positions seemed to be acceptable as it gave her permission to also have a child who experiences difficulties, and there was less fear that she was going to be judged as a bad parent. In the quote below, Amal is describing how easy it felt for her to talk about the sleep problems in a parents’ meeting arranged by the sleep service, but that this ease was specific to this setting:

> Erm because when I, I used to attend, to attend the parent's meeting here and then every time different person, different problems, different, and then I take my problems because we are here parents meeting all with the parents which has the child with the disability, and then I tell my, because we all, they ask us what is your problem what do you do how you spend your time how is that how is that, so we tell (Amal, 232 – 239)

3.5.3. Visible versus Invisible Differences

For some parents the concepts of visible and invisible differences seemed to exemplify the way in which they understood others' perceptions of their child's difficulties:

> Because he looks so normal, they think he's normal, they don't understand the problems that he's got (Karen, 507 – 509)

This felt problematic for Karen as it meant that her son, who had a label of ASD, was not understood and she had to work hard to help others understand his perspective. Both Sara and Karen spoke about how it seemed easier when people had visible differences:

> Sometimes I wish he looks disabled, and I know that's really horrible, because then what people see is what they understand, not the other way around (Karen, 541 – 544)

> It's not just about physical disabilities, I think the invisible disabilities are even harder sometimes, no not even harder but a different hard [I: Yeah, it means different things] It means different things has a different impact, you know his behaviour is looked on as either odd or bad rather, you know, if he was in a wheelchair then he would be allowed, there would be allowances made sometimes. Not that I wish that but. (Sara, 492 – 501)

It seems there is an idea that people with visible differences are allowed to have difficulties, whereas this was not the case for Karen and Sara's children meaning that they had to battle to help others understand their child so they were not thought of as simply 'bad'. Implicit in this is a sense of being judged, which resonates with the idea of being a good enough parent and how this was made difficult for Karen and Sara. This potentially had a knock-on effect for how they felt judged by services, and influenced how and when they sought help.

3.6. Summary of Key Findings

The key findings of the research are listed under the research questions below:

- Does parenting a child with disabilities and sleep problems have any influence on experiences of parenting and help-seeking?
    - Parents experience a lot of pressure to ‘do’ parenting well
    - The context of parenting a child with disabilities eclipses any other concerns or issues

- How do parents of children with disabilities and sleep problems identify and talk about problems with sleep?
    - Parents find it difficult to identify sleep problems and are unaware of the associations between sleep problems and disabilities

- What are the reasons parents of children with disabilities and sleep problems seek-help and engage with sleep interventions?
    - Parents are not aware that services specifically designed to offer support with sleep problems are available

These key findings will be fully explored in the next chapter.

4. DISCUSSION

4.1. Overview

This study set out to explore how parents identify and talk about problems with sleep and what influences the process of seeking help for the sleep problems of

a child with disabilities. Nine interviews with 10 parents were conducted. Following a thematic analysis of the interviews, five themes were constructed: 'Identifying Sleep as a Problem', 'How to do Parenting', 'Escalation of the Sleep Problems: Eliciting a Help-Seeking Response', 'Can you get Help for Sleep Problems?' and 'The Context of Parenting a Child with Disabilities'.

A summary of the key findings and how they relate to the research questions and previous literature will be discussed below. This will be followed by a discussion of the implications of this research given the strengths and limitations, alongside a consideration of issues of reflexivity.

4.2. Summary of Findings

4.2.1. Parents experience a lot of Pressure to 'do' parenting well

Parents' experiences seemed to be greatly organised by society's constructions of the best way to parent your child and the ideal of being a 'perfect parent'. This seemed to be the case across cultures as the parents in this study spoke about their experiences in the UK but also abroad (Asia, Europe, Israel) where these values were upheld. Implicit within these constructions are the assumptions that parents should know how to cope with any of their child's difficulties and should know how to make them 'better' (Pavluri et al., 1996); if you cannot, you are understood to be a 'bad' parent. The narrative that you are a 'bad' parent also arises from being a parent of a child with disabilities as this implies some degree of weakness and fault in you (Thurer, 1995).

Although not explicitly described by parents as the stigma of being a bad parent, it seems that this was something that most of them felt; they identified with having a child who differed from a typically developing child and feeling incompetent for not being able to help their child. The way in which these parents approached seeking-help seems to have been influenced by these experiences of stigma (Dempster et al., 2013) as it made them reluctant to share their difficulties until they had reached a point of unmanageable intensity.

Help seeking was also influenced by ideas about who takes care of children. Although it is simplistic to assume a binary divide between individualism and collectivism (Tamis-LeMonda et al., 2008), research does suggest there are different cultural values (Markus & Kitayama, 1991; Lerner & Ashman, 2006). Greif (1994) describes individualist cultures as the “Developed West” (p. 913), and this includes countries such as UK and USA; collectivist cultures are more likely to be found in countries such as Korea and Israel. In more individualist cultures there is an emphasis on independence; this is in comparison to ideas about inter-dependence being privileged in collectivist societies (Markus & Kitayama, 1991; Lerner & Ashman, 2006). The parents in this study were organised by this individualist belief as they assumed an autonomous and independent position, whether they were from a pre-dominantly individualist culture (for example UK or Australia) or a pre-dominantly collectivist culture (for example Israel or India), and this stopped them from seeking help as soon as they had any concerns; they assumed that this was a task for them to handle. If they were unable to conform to this, they would consider themselves to be lazy or indolent. Parents also seemed to believe that when they did seek help, it was important for them to remain an active participant in the process and still endeavour to help their child, alongside professionals.

The participants commented upon the role of primary caregiver. Gender constructions may have influenced which parent assumed the role of primary caregiver. In eight of the nine parent couples, the mother was responsible for providing the majority of care to their child with disabilities and sleep problems. The males in the parent couples were more likely to be responsible for providing financial support. It is possible that these positions were influenced by conformity to gender stereotypes, which suggest that women are more likely to be caring and can be the ‘ideal mother’ (Thurer, 1995; Williams, 2006) who acts for others, especially her children. Men on the other hand, may have been influenced by stereotyped ideas about them being providers and less emotionally available. However, due to the nature of this study, there was not scope to fully explore these hypotheses, so they are limited and risk reducing complex processes to binary roles. What is of note here, is that despite ideas that women are more likely to seek help, when compared to men (Jackson,

2011), the mothers in this study were reluctant to seek help because of the over-riding influence of the issues mentioned in this discussion: they were not aware they could ask for help, it was hard to identify sleep as a problem and the context of parenting a child with disabilities, which was the same for the fathers.

These narratives about parenting seem to be a key factor in understanding parents' reasons for seeking-help as they occur across all of the main findings. The ways in which these narratives further influenced help seeking will therefore be described below.

4.2.2. The Context of Parenting a Child with Disabilities eclipses any other Concerns or Issues

While this study and the interviews focused specifically on sleep difficulties, all parents spoke about this in the context of their child's disability. Parenting a child with disabilities was spoken about because of the experiences of loss, anger, stress and emotional distress associated with it. For some of these parents, feelings of anger and loss were associated with their child receiving a label of disability. Research suggests that parents can experience feelings of both relief and devastation when their child is given a label (DePape & Lindsay, 2015); relief because they have an answer or a framework within which to understand how to best support their child, but also devastation because of the common understanding that disabilities are lifelong and unchangeable conditions (De Pape & Lindsay, 2015). According to the Family Life Cycle approach (Carter and McGoldrick, 1988) families often develop problems at the transitions stages. In families where there is a child with disabilities, these transitions and expectations of punctuating milestones have been disrupted because of the differences in the child's emotional, physical and social development, which can intensify the challenges associated with the transition (Miller, Gordon, Daniele, & Diller, 1992). This can result in feelings of loss and anger, as well as increased stress as the family works to restore equilibrium.

Parents made reference to this context when they spoke about their experiences of stigma and discrimination. Parents suggested that those in their wider system, such as family members and professionals, as well as the public,

were not understanding about issues of difference. This was challenging for these parents as they found it very distressing when their child was treated differently and not accepted by others. For some the issue of visible and invisible differences was particularly salient. They commented on how people expect those children who do not look different to behave in a 'normal' way, and when they do not, they assume they are 'bad' or 'naughty', and parents often feel that they are to blame as a result (Sorin, 2005). This suggests that the parents feel as though services, and perhaps society, are not set up to support or understand their children, which could make them less likely to seek help as people need to trust that the services they are accessing are knowledgeable, experienced and effective (Contact a Family, 2011). When invisible differences (Stone, 1995) and implicit norms in society (Martz, 2001) are unacknowledged, this contributes to the oppression and discrimination of those individuals, which intersects with the subjugation they are already facing to increase the adversity they experience (Stone, 1995; Martz, 2001; Taleporos &McCabe, 2002).

Parenting a child with disabilities also speaks to the idea of being a 'perfect parent' that was identified above and in theme two (see section 3.2. for a full description). When children have difficulties, or are 'bad', parents can internalise experiences of blame that they have not done a good enough job of raising their child, and judgments that they are not a competent parent. Inevitably these descriptions of oneself become expressed in feelings of guilt, shame and sadness. The emotional toll on these parents is great; it is not surprising that their child's sleep problems fall down the list of priorities when there are so many other issues to contend with.

Related to this, parents commented on how it was difficult to talk to others about the difficulties their child had, unless the person was in a similar position to them. It seems this was because of a fear of not being understood, or exacerbating feelings of difference. Unsurprisingly this resulted in feelings of isolation for some parents. For others it triggered a need to operate outside of the family system so that they were free to be themselves without being viewed through the lens of a parent of a child with disabilities and sleep problems; this was important for them as they felt that their identity and capabilities had been constrained by this lens. Through minimising the occurrence of difficulties,

parents may be unintentionally contributing to the maintenance of the unacknowledged wish to hide differences because they are undesirable; a consequence of this could be that parents are not exposed to extra support from others, which they may need, especially as it seems to take a long time before they can access support from professionals.

Parents also referred to the context of parenting a child with disabilities because, in most of the cases, it was the primary reason they were in contact with services. It was through conversations related to their experiences of parenting their child that discussions about sleep problems arose. Research recognises that these parents are under considerable stress and strain (Keenan et al., 2007) and face unique challenges. The experience of parenting a child with disabilities and sleep problems means that the sleep problems become one of many battles for these parents, and the decision to seek help for them, often does not come until much later. As a result of this, the effects of the sleep problem often become a way of life and something that parents find a way to manage, in spite of the emotional and physical burden it places on them and their families. It seems to be understandable then, that parents who are trying to manage the adjustment to parenting a child with disabilities, both in terms of emotional responses and physical and practical demands, will find it difficult to prioritise anything other than trying to manage these overwhelming struggles.

4.2.3. Parents find it difficult to identify Sleep Problems and are unaware of the associations between Sleep Problems and Disabilities

A barrier to parents seeking help seems to be that it is difficult to identify when there is a problem. Researchers have previously noted that parents can experience challenges with this (Wiggs & stores, 1998), but the reasons remained unclear. The parents in this research commented that when they began to suspect their child was experiencing difficulties in relation to their sleep it was important to ascertain whether it was normal or not. This way in viewing behaviours as either normal or abnormal is in line with a medical model understanding of disabilities. The parents sought explanations for their child's sleep problems that were 'normal', such as wet nappies, alterations in the sleeping arrangements, anxiety about school or behaviours that were 'normal'

for their developmental age. This also applied to the way the child's gender was thought to influence their behaviour; for two of the parents of boys for example, their concerns were minimised because of the dominant narrative that 'boys will be boys' and are allowed to be active and energetic. The ideas that these sleep patterns were 'normal' seemed to be reassuring for parents, as it indicated that their children were behaving in a customary manner and so removed any need to seek help. It may have been useful to them because it meant they did not need to expose themselves to potential scrutiny and judgment about being a 'bad' parent (Peckover, 2002). Furthermore, it is understandable that parents would want to view their child as 'normal' because of the connotations of being described as 'abnormal' and consequential experiences of 'othering'; 'othering' in this context refers to how difference (disabilities and sleep problems) can be pathologised, resulting in stereotyping of individuals, discrimination and social distancing (Jenson, 2011). The parents in this study may have been attuned to this because the reality that their child has a disability may already have resulted in experiences of being 'othered'. Whilst this normalisation of behaviour seemed helpful to parents, it also meant that their child's difficulties were not named as such and so interventions targeted at this, were not implemented; the consequences of the sleep problems continued contributing additional levels of stress to the families.

The overarching context of disability also seemed to hinder parents' abilities to name sleep as a problem. For some parents, all difficulties were viewed through the lens of disabilities, which meant that the impact the sleep problems could have on other areas of the child's functioning was minimised, such as their cognitive functioning. This is despite the wealth of literature which highlights the significant impact a child's sleep problems can have on their parents' and family's mental, physical and emotional well-being (Stores, 2002; Doran, Harvey & Horner, 2006; Goldman et al., 2011; Taylor et al., 2012). For Iris, it was important to focus on helping her child manage with a world that is organised around typically developing individuals. This was perhaps to minimise any distress he experienced, but also, any feelings of difference. Prioritising this was important for her, and other parents, and meant that sleep difficulties were overlooked, in spite of the impact they can have on these areas. This suggests that there is a gap between what professionals and

researchers know about this impact, and what the parents living in these situations are aware of.

Viewing difficulties through this lens also seemed to indicate that the biological deficit model organised parents' understandings of their child's sleep difficulties, which resulted in ideas that the behaviours cannot be changed. This is in accordance with research, which suggests that parental attributions about causes of difficulties and their likelihood for change influence help-seeking behaviour (Reimers, Wacker, Derby & Cooper, 1995). It seems to be that parents make the assumption that they need to tolerate the difficulties rather than viewing them as something they can get help for (Quine, 1991).

4.2.4. Parents are not aware that Services specifically designed to offer support for Sleep Problems are available

The UK literature suggests one reason why parents do not access support for sleep problems is because of their concerns about the effectiveness of the intervention (Beresford et al., 2010). The analysis from this research seems to indicate the issue precedes this, as parents are not aware services that can offer these interventions even exist. This lack of awareness seemed to have a twofold effect. On the one hand it meant that when parents were in need of help, they did not know there was a service they could turn to, which could offer them assessment and intervention. This meant that parents continued trying to manage the difficulties on their own; these difficulties will be described below.

The findings from this study are in accordance with previous research findings, which suggest that sleep problems can have profound impacts upon parents, children and their families (Stores, 2002; Doran, Harvey & Horner, 2006; Hodges et al., 2013; Lee, 2013). Parents felt incredibly overwhelmed by the sleep problem and the impact it had upon them; it prevented them from leading the lives they wished to lead and made them feel trapped and powerless. In addition to this, parents spoke about the physical toll on their bodies and how this left them feeling as though they had been "unplugged" (Renee, 383) (see page 62 for a direct quote) from an energy source and exhausted. The sleep problems had adverse effects on their spousal relationships due to rising

tension between them, and many did not sleep together because they were tending to the child with sleep problems. There were also effects on the siblings of the child with sleep problems that had resulted, in one case, in complaints from school about the sibling's lack of concentration.

Taken together, these are considerable demands on parents. Their resilience in the face of them was striking, and it was not until parents found the impacts completely unbearable that they sought help (in that they mentioned the sleep problem to professionals in passing). For some parents the support of their spouse was cited as something that helped them to cope with these, for others it was resignation that this was how life had to be.

The concept of being a 'perfect parent' also implies an element of self-sacrifice, society's understanding of parenting roles is that they must do whatever they can for their child, no matter what the consequences are; This construction may have contributed to this tolerance and resilience in the context of a high level of difficulty. What is interesting is that when parents did alert professionals to the challenges they were facing, the majority did so when the experiences became unmanageable for them, not their child. It is possible that the value of doing the best for your child was interpreted at this point, as 'helping yourself to help them', which gave them permission to seek additional support, in spite of the conscious or unconscious misgivings they may have held about it.

The second aspect of the lack of awareness of specialist sleep services seemed to organise parents' conceptualisations of sleep as a problem: if there is not a service that can help, it must mean that this is not considered a problem. The majority of parents in this study did not directly seek help for sleep problems, how can one be expected to ask for help when they do not know that help exists. This point addresses the issue that the parents in this study were dependent and reliant on services to be attuned to the difficulties they were bringing, even when they were not directly about sleep problems, and listen out for any other concerns. The UK context of the NHS and free healthcare is most often based on a professional-to-professional referral system; these services were not the specialist sleep services, so there was an assumption that professionals working in GP practices, paediatric clinics and general child

disability teams, had this knowledge about the link between sleep problems and disabilities and could readily refer families on. This places a lot of pressure on already over-burdened systems that are struggling to deal with demand and capacity issues.

A further point here relates to the issue of professional power. Parents accessing help in this way relies on an agreement between parents and professionals about how problems are conceptualised; in this study parents appeared to be relieved when the professionals identified a problem as it fit with their experiences, although this is contrary to the literature which suggests that professionals often ignore parents' subjective experiences and focus on diagnostic criterion to assess the problematic behaviours in the child (Pavuluri et al., 1996; Chervin et al., 2001; Richdale & Baker, 2014). Relying on professionals to identify and name problems for parents can be seen as reducing their power in the situation and may limit how able they feel to deal with the problems. These parents may already be feeling disempowered due to the nature of being a parent of a child with disabilities; two parents in this study spoke of feeling as though they had been forced into a parallel world of parenting where nothing was as you expected it to be and so you had to start again and learn new skills from the beginning. Another asked for a "dummies guide" (Martin, 601. See page 46 for a direct quote) to help direct them and offer them guidance. Feelings of disempowerment may add to experiences of incompetence and further undermine parents' roles in taking care of their children.

4.3. Limitations

4.3.1. Demographics of the Sample

Homogeneity of the sample is often seen as a positive in research because it allows for a focus on the issues being explored. In this research the parents were all the main caregivers, or shared caregiving responsibility equally and were all in supportive co-parenting relationships. Parents spoke about how

challenging and distressing it can be raising a child with disabilities; considering the perspectives of parents who do not receive similar support or are under additional pressures could extend the findings of this research. Some parents in the study spoke to this when commenting on their respect of single parents and parents who are in employment as well as being main caregivers. It would be interesting to explore if these parents experience additional difficulties in identifying problems, seeking help, or pressure in conforming to society's norms of parenting, in the context of having a child with disabilities, and to consider how services can respond to this. This sample was also an English-speaking sample, and one participant spoke about the difficulties he had accessing services and support even though he could speak the language and he wondered what it would be like for others who do not. One could hypothesise that not speaking English would limit a parent's ability to seek help and increase the burden on them; suggesting this is an important direction for future research to take.

Although the participants reported identifying with different ethnicities, cultural differences did not appear to be a significant factor in how these parents spoke about their experiences. They all seemed to uphold similar beliefs about parenting roles and responsibilities and strived to achieve similar levels of 'parenting perfection'. There was some difference in terms of how "taboo" the topics of sleep problems and disabilities were perceived, but most of these parents described feeling misunderstood by others and struggling to communicate their difficulties. Research done with more parents, from different locations could perhaps shed some light on whether these findings are typical for a UK based population of various ethnicities, or if cultural differences can have more of an impact on experiences of parenting, sleep problems and help-seeking.

This sample was not homogenous in terms of the disabilities the children had. The decision for this was based on the literature (Tietze et al., 2012; Richdale & Baker, 2014), which suggests that sleep problems are prevalent in this population, independent of the type of disability they have

4.3.2. Issues of Recruitment

Initially I hoped to interview parents who had engaged with sleep interventions, and those who had been referred to the service but did not subsequently engage with the interventions. However, the participants who volunteered to take part had all engaged in some way with sleep interventions. Due to time constraints on the recruitment period, it was not possible to continue recruitment, which might have meant that others who did not engage with the sleep interventions would have decided to participate and thus the results are skewed in this way. Whilst this was helpful for maintaining a degree of homogeneity about the sample, it is important to consider that these parents may have been more motivated to persevere with seeking help and then engaging with interventions; other parents may have experienced similar difficulties in initially identifying sleep problems, but then found it harder to continue to seek the help they needed. The reasons for why they might not have engaged therefore remain unknown but the literature suggests that these parents may have spoken about difficult relationships to help influenced by cultural and personal beliefs (for example about professionals not being useful), physical barriers to engaging or more firmly held beliefs about the unlikelihood that the situation can change.

A further limitation arises due to the fact that all participants were recruited from the same service and lived within the same inner-city borough. Whilst there were some differences in terms of socio-economic status, the findings are limited in terms of their generalisability and the amount one can extrapolate from them. This study recruited from a single site because of the lack of specialist sleep services for children with disabilities, which limited recruiting options, and this study was exploratory in nature. It may be interesting to consider the possibility of conducting interviews with parents in similar situations but different locations to consider the impact of their environmental contexts on this process, and whether the existence, or not, of a sleep service in that area makes any difference to their help-seeking. For example, through support groups or generic Child Learning Disabilities services.

4.4. Strengths

4.4.1. Evaluation against Guidelines for Good Practice in Qualitative Research

Qualitative research has been accused of lacking credibility, as it does not match the exacting methodological standards of more scientific, quantitative approaches (Elliott et al., 1999). Several authors have sought to find means in which the value and integrity of qualitative research can be upheld; Elliott et al. (1999) have developed a set of guidelines for good practice, which research can be evaluated against. Conformity with these principles of good practice does not equate to an exemplar study but hopefully demonstrates a level of quality; as such this thesis will be evaluated against these guidelines:

4.4.1.1. Owning one's perspective

Qualitative research cannot be carried out void of the researcher's own beliefs, assumptions and values. Instead it is appropriate to name these to allow the reader to understand the interpretations the researcher has made about the data and alternatives to this. In this thesis, I set out my epistemological position at the beginning and shared elements of my experiences, which have shaped my values and beliefs, thus making attempts to be transparent about why I made certain interpretations about the data. I have included a section on reflexivity where I further reflect on my role in the process and the influence this had.

4.4.1.2. Situating the sample

In order to aid the reader's decisions about the generalisability and relevance of the research, it is important to describe the sample in terms of basic demographics and any information that is pertinent to the research. Here I have described the sample and the means in which they were recruited, alongside information deemed relevant based on the literature review. I have also commented on the limitations of this sample and how this influences its generalisability.

4.4.1.3. Grounding in examples

Throughout the results section quotations were used to illustrate the themes and subthemes that were constructed and to demonstrate the process of analysis and interpretation through the commentary on specific quotes. Multiple quotes were used to illustrate some themes and subthemes, so that the pattern could be seen across the dataset, and so that the reader could see that one interviewee's comments were not privileged over another's. Quotations were of reasonable length to avoid them seeming as though they were taken out of context.

4.4.1.4. Providing credibility checks

My supervisor, who has knowledge and experience of using TA and conducting research in the field of disabilities, checked the analysis; comments and feedback were provided and discussed. An audit trail of the analysis is included in the appendices (examples of transcription, coding and development of themes) (see Appendices B, C, D and E). Credibility checks were conducted throughout the interviews via a process of checking in with participants about my understanding of the meaning of their comments. The participants were also offered the opportunity to comment on the constructed themes; one participant responded to this.

4.4.1.5. Coherence

Coherence was achieved through a process of reviewing and refining candidate themes in the analysis and organising them around unifying concepts. A thematic map (see Appendix E) was developed positioning themes that related to one another in close proximity; this then informed the organisation of the narrative of the data. I have attempted to signpost the reader to any relationships and overlaps.

4.4.1.6. Accomplishing research tasks

The aim of this study was to explore reasons for parental help-seeking for children with disabilities and sleep problems; whilst this general aim was

achieved through the identification of themes across the participants, attention was also paid to differences in the participants' experiences, in order to attend to intersections of participants' context's, such as gender. This was important for signaling the extent to which these findings can be transposed onto others.

4.4.1.7. Resonating with readers

My experiences working with families who have children with disabilities and professionals in this field, permits me to think that this research is rich and interesting. Moreover, the links to previous research suggest this topic is noteworthy in current fields of study. Throughout the process I have submitted draft chapters to my supervisor and have received favourable comments, as well as feedback about his emotional experiences when reading the results chapter in particular. It is not possible to know at this stage whether it resonates with a broader readership, this will hopefully be achieved if the research is given a favourable assessment and can be disseminated to the sleep service and academia through publication.

4.5. Implications of this Research

4.5.1. Implications For Clinical Practice

4.5.1.1. Disabilities take priority

The parents in this study all described the continuing impact parenting a child with disabilities has on their lives, from being given a label or diagnosis as a baby to transitioning to adult services. It is not suggested that services do not attend to these experiences, but when thinking about low engagement and high dropout rates for sleep interventions, services must consider where the sleep problem sits in the list of parental priorities and what other stressors or emotions they are experiencing. Parents overwhelmingly spoke about how they must 'pick their battles', but at the same time, it is far from ideal that parents are not receiving help for sleep problems until the impact of them reaches an unbearable intensity. Services could take a role in asking about sleep problems

and drawing parents' attention to them in a bid to prevent some of this increased difficulty. Children with disabilities commonly have a number of appointments to attend, given the knowledge professionals have about sleep problems in children with disabilities they need to share some of the responsibility with parents and encourage questions about child and parental sleep, and the impact of these, to become part of routine assessments.

Services could also play a role in helping to better manage parents' expectations at the start of interventions. Parents spoke about wanting whatever help they could get, as they were desperate for change. However, change in sleep behaviours takes time and "perseverance", as one parent eloquently described it. By making this clear to parents, services could alleviate any feelings of disappointment, which may also be contributing to drop out rates.

4.5.1.2. Lack of awareness

There is also the issue that parents lack an awareness that sleep problems can be ameliorated, that services for sleep problems exist and information on how to access them. Services must strike a balance between not offering a surplus of information at a time when parents feel unable to retain it, and providing enough information so that it can be useful to parents. There is also the dilemma of striving to increase parents' sense of status and power in the parent-professional relationship. One way in which services could achieve this is by working with parents who have experienced these difficulties as consultants. Not only does this fit with the emphasis on service-user involvement in the NHS (NHS Constitution for England, 2013) but it also fits with the descriptions of some parents in this study that the most useful support and advice they received was from other parents. This may have been due to smaller power differentials between parents and parents, compared with parents and professionals; furthermore, hearing experiences from other parents may increase the sense that their concerns are legitimate and helps to normalise and validate their experiences. As the NHS moves towards a more consumer-led approach to healthcare provision, it is important for professionals to ensure parents are aware of services that can offer them help and support, to avoid parents enduring challenges on their own.

Service-User Consultants or Experts by Experience could use their experiences to share with others what sleep problems might look like, how they might feel, possible effects on others in the system, how to get help, what help looks like and what to expect. This could be done, in conjunction with a sleep service, through the design of a leaflet or parents could be encouraged to write blogs or create an online forum and sleep advice page; the increasing use of social media in modern society allows for rapid dissemination of material. Accessible leaflets such as Montgomery and Wigg's (2007) leaflet on 'Encouraging Good Sleep Habits in Children with Learning Disabilities' is a good example of sharing information, strategies and support networks with parents. These materials would then be available to parents who engage with services, but also those who do not, yet still require support.

It is essential that this information is also disseminated to primary care staff who have numerous contacts with parents of children with disabilities and sleep problems, such as GP's, Health visitors, Family Support Workers and School Nurses. Providing staff in these settings with information about the links between sleep problems and disabilities as well as service user-led material, means that they can be supported to provide early identification of sleep problems alongside useful interventions and strategies, which for some, may usefully negate the need for specialist services and reduce the number of contacts these parents are obliged to have with professionals.

4.5.2. Implications for Research

Based on the limitations of the sample, it would seem prudent to conduct research that explores the experiences of single parents and other minority parent groups, such as gay or lesbian parents. The aim of this would be offer a richer account of parents' experiences of parenting a child with disabilities and sleep problems and what encourages them to seek help for these difficulties. The findings suggest that parents feel under pressure to conform to parenting norms, so the experiences of these parents who already diverge from these norms may be unique and offer different accounts of the experiences of stigma and discrimination.

Exploring the perspectives of parents who have identified problems but have never asked for help or have been referred to specialist sleep services by professionals but not engaged with interventions, would also be an interesting line of research; exploring whether or not these parents experience similar impacts of the sleep problem, pressure to conform to society's ideals, whether or not there are any protective factors that mediate their experiences, or whether there are additional barriers to help seeking experienced by this group, could be useful for services to be aware of in terms of thinking about the needs of 'at risk' groups and could influence how and when they offer support.

4.6. Issues of Reflexivity

4.6.1. My Role as a Clinician versus Researcher

My previous experiences and current training have primed me to be attentive to people's stories. During this research process, I was aware of an internal dilemma between stopping at this point and not offering validation, reassurance, and advice as I might have done if the interviews had been clinical sessions. This subtle difference was difficult for me, particularly when parents were describing distressing experiences. I wonder if the fact that parents knew I was a Trainee Clinical Psychologist, as this was the designation I used to sign off on documentation, led them to assume that I would be empathic and supportive. When this is considered alongside my somewhat automatic posturing as a therapist, and my vested interest in understanding that parents are doing the best they can for their children, it is possible that the interviews were biased to elicit stories of distress, painful experiences and difficulties. This potential effect was hopefully mediated by my preference for critical approaches (for example narrative therapy and community psychology), which offers ways in which to attend to aspects of difference and resistance. By asking questions such as "what difference did that make for you", I was attempting to create space for alternative descriptions to be heard as well.

4.6.2. Western Ideals

In the statement of positioning, I named a number of contexts that I considered to be relevant to this research. I did not name that I am of White British Ethnicity and from a Western society. It seems important to mention this here as I am aware that Western ideals and norms have been a thread running through the literature review, results and discussion chapters; and it is possible that I was listening out for examples of these in the interviews. Whilst the values of what makes a good parent and norms about gender, children and parenting responsibilities are familiar to me, and in many ways correspond with some of my experiences, I have tried to remain critical and not take some of the assumptions inherent in these ideas for granted. By making some of these assumptions explicit, such as 'children as cherubs', it is hoped that this research adds to the critical movements whereby people can challenge traditional ideas about how they should live their lives and create richer narratives of themselves. For example, one parent spoke of her worry about being a "crap parent", yet I was struck by how much thought she put into trying to understand her child and her efforts to notice his moments of creativity and resilience.

4.7. Conclusion

It is hoped this study has shed some light on the experiences of parenting a child with sleep problems and disabilities and the contexts that organise the way in which these experiences are talked about. The process of parental help seeking for sleep problems is complex and dependent on a number of factors including the knowledge and availability of services. It is hoped that this study can contribute towards developments in children's disability and sleep services by making information about sleep problems in children with disabilities more accessible, either through broader dissemination of the material (leaflets, blogs) or by making services more accessible and parents more aware of them. It is also hoped that other services can be supported to take up the role of helping parents to identify these difficulties, and provide effective support. This study can hopefully contribute to the UK and wider parenting, disability and sleep

research by highlighting the areas where more research is needed and the difficulties in recruiting participants who have not engaged with services.

REFERENCES

Abbott, D., Morris, J. & Ward, L. (2000). *Disabled Children and Residential Schools: A survey of local authority policy and practice.* Bristol: Norah Fry Research Centre, University of Bristol

Ahern, K. J. (1999). Pearls, Pith and Provocation: Ten tips for reflexive bracketing. *Qualitative Health Research, 9,* 407 – 411.

American Academy of Sleep Medicine (2001). *International Classification of Sleep Disorders revised: Diagnostic and coding manual.* USA: American Academy of Sleep Medicine.

Angold, A., Messer, S., Stangl, D., Farmer, E., Costello, E. & Burns, B.

(1998). Perceived parental burden and service use for child and adolescent psychiatric disorders. *American Journal of Public Health, 88, 75 – 80.*

Arcia, E. & Fernandez, M. C. (1998). Cuban mothers' schemas of ADHD: development, characteristics and help-seeking behaviour. *Journal of Child and Family Studies, 7,* 333- 352.

Baker, B.L., McIntyre, L.L., Blacher, J., Crnic, K., Edelbrook, C. & Low, C. (2003). Pre- school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*, 217 - 230.

Banister, P., Bunn, G., Burman, E., Daniels, J., Duckett, P., Goodley, D., … Whelan, P. (2011). *Qualitative Methods in Psychology: A research guide* (2nd edition). Berkshire: Open University Press.

Barnes, J., Katz, I., Korbin, J. & O'Brien, M. (2006). *Children and Families in*

Communities: Theory, research, policy and practice. West Sussex: Wiley.

Bartlett, L. B., Rooney, V. & Spedding, S. (1985). Nocturnal difficulties in a population of mentally handicapped children. *British Journal of Mental Subnormality, 31*, 54 - 59.

Benoit, D., Zeanah, C. H., Boucher, C. & Minde, K. K. (1992). Sleep disorders in early childhood: Association with insecure maternal attachment. *Journal of American Academic Child and Adolescent Psychiatry, 31,* 86 - 93.

Beresford, B. (2009). *The Effectiveness of Behavioural Interventions which Involve Parents in the Management of Behaviour Problems among Disabled Children: A rapid review*. Working paper. York: University of York, Social Policy Research Unit.

Beresford, B., Stuttard, L., Clarke, S., Maddison, J. & Beecham, J. (2012). *Managing Behaviour and Sleep Problems in Disabled Children: An investigation into the effectiveness and costs of parent-training interventions*. London: HM Stationery Office.

Blum, M. J. & Carey, W., B. (1996). Sleep problems among infants and young children. *Paediatrics in Review, 17,* 87 – 92.

Blunden, S. L., Thompson, K. R. & Dawson, D. (2011). Behavioural sleep treatments and night time crying in infants: Challenging the status quo. *Sleep Medicine Reviews, 15,* 327 – 334. doi: 10.1016/j.smrv.2010.11.002

Bramble, D. (1996). Consumer opinion concerning the treatment of a common sleep problem. *Child: Care, Health and Development, 22,* 355 – 366. doi: 10.1111/j.1365-2214.1996.tb00438.x

Bramble, D. (1997). Rapid acting treatment for a common sleep problem.

Developmental Medicine and Child Neurology, 39, 543 – 547.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77 – 101.

Braun, V. & Clarke, V. (2013). *Successful Qualitative Research: A practical guide for beginners*. London: Sage

Braun, V. & Clarke, V. (2015). *Thematic Analysis*. Retrieved from: http://www.psych.auckland.ac.nz/en/about/our-research/research-groups/thematic-analysis.html

Brisenden, S. (1986). Independent living and the medical model of disability. *Disability, Handicap and Society, 1,* 173 – 178. doi: 10.1080/02674648666780171

British Psychological Society (2009). *Code of Ethics and Conduct*. Leicester: BPS

Broadhurst, K. (2003). Research review: Engaging parents and carers with support services: Lessons from research on help-seeking. *Child and Family Social Work, 8,* 341 – 350.

Brown R. I., Schalock R. L. & Brown I. (2009). Quality of Life: It's application to persons with intellectual disabilities and their families – introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities 6*, 2 – 6

Bury, M. (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness, 23*, 263 – 285

Capdevila, O. S., Kheirandish-Gozal, L., Dayyat, E. & Gozal, D. (2008). Pediatric obstructive sleep apnoea: Complications, management, and long-term outcomes. *Proceedings of the American Thoracic Society, 5,* 274 – 282. doi: 10.1513/pats.200708-138MG

Carter, B. & McGoldrick, M. (1988). *The Changing Family Life Cycle: A framework for family therapy* (2nd ed.). New York: Gardner Press

Chavin, W. & Tinson, S. (1980). Children with sleep difficulties. *Health Visitor, 53,* 477 – 480.

Chen, M. L., Carmichael Olson, H., Picciano, J. F., Starr, J. R. & Owens, J. (2012). Sleep problems in children with Fetal Alcohol Spectrum Disorders. *Journal of Clinical Sleep Medicine, 8,* 421 – 429. doi: 10.5664/jcsm.2038

Chervin, R., Archbold, K., Panahi, P. & Pituch, K. (2001). Sleep problems seldom addressed at two general paediatric clinics. *Paediatrics, 107,* 1375 – 1380.

Chervin, R. D., Ruzicka, D. L., Giordani, B. J., Weatherly, R. A., Dillon, J. E., Hodges, E. K., … Guire, K. E. (2006). Sleep-disordered breathing, behavior, and cognition in children before and after adenotonsillectomy. *Pediatrics*, *117,* 769 - 778.

Chou, Y. C., Pu, C. Y., Lee, Y. C., Lin, L. C., & Kroger, T. (2009). Effect of perceived stigmatization on the quality of life among ageing female family carers: A comparison of carers of adults with intellectual disability and carers of adults with mental illness. *Journal of Intellectual Disability Research, 53*, 654–664.

Chu, J. & Richdale, A. (2009). Sleep quality and psychological wellbeing in mothers of children with developmental disabilities. *Research in Developmental Disabilities, 30,* 1512 – 1522. doi: 10.1016/j.ridd.2009.07.007

Clarke, V. & Braun, V. (2013). Teaching thematic analysis: Over-coming

challenges and developing strategies for effective learning. *The Psychologist, 26,* 120 – 123.

College Report (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists). (2007). *Challenging Behaviour: A unified approach.* London: Central Executive Committee.

Contact a Family (2011). *Forgotten Families: The impact of isolation on families with disabled children across the UK.* London: Contact a Family

Contact a Family (2011). *Putting families with disabled children at the heart of the NHS reforms in England*. London: Contact a Family

Contact a Family (2016). *Facts about families of disabled children and young people.* Retrieved from: http://www.cafamily.org.uk/professionals/research/

Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: Science and Practice, 7,* 48–67.

Corkum, P. Davidson, F. Tan-MacNeill, K. & Weiss, S. (2014). Sleep in children with neurodevelopmental disorders: A focus on insomnia in children with ADHD and ASD. *Sleep Medicine Clinics, 9,* 149 – 168. doi: 10.1016/j.jsmc.2014.02.006

Cotton, S. & Richdale, A. (2006). Brief report: Parental descriptions of sleep problems in children with autism, Down syndrome, and Prader- Willi syndrome. *Research in Developmental Disabilities, 27*, 151 – 61.

Courtenay, W, H. (2000). Constructions of masculinity and their influence on

men's wellbeing: A theory of gender and health. *Social Science and Medicine, 50*, 1385-1400

Cox, A. D. (1988). Maternal depression and impact on children's development. *Archives of Disease in Childhood, 63*, 90 - 95

Crenshaw, K. (2012). *On Intersectionality: the essential writings of Kimberle Crenshaw*. New York: New Press

Crowe, T. K., & Florez, S. I. (2006). Time use of mothers with school-age children: A continuing impact of a child's disability. *American Journal of Occupational Therapy, 60,* 194 – 203. doi: 10.5014/ajot.60.2.194

Cunningham, C. E., Boyle, M., Offord, D., Racine, Y., Hundert, J., Secord, M. & McDonald, J. (2000). Tri-ministry study. Correlates of school-based parenting course utilization. *Journal of Consulting and Clinical Psychology, 68,* 928 – 933.

Dempster, R., Wildman, B. & Keating, A. (2013). The role of stigma in parental help-seeking for child behaviour problems. *Journal of Clinical Child and Adolescent Psychology, 42,* 56 – 67. doi: 10.1080/15374416.2012.700504

DePape, A. & Lindsay, S. (2015). Parents' experiences of caring for a child with Autism Spectrum Disorder. *Qualitative Health Research, 25,* 569 – 583. doi: 10.1177/1049732314552455

Department for Work and Pensions (2008). *Exploring disability, family formation and break-up: Reviewing the Evidence*. London: HM Stationery Office

Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: HM Stationery Office

Diala, C., Muntaner, C., Walrath, C., Nickerson, K., LaVeist, T., & Leaf, P. (2000). Racial difference in attitudes toward professional mental health care in the use of services. *American Journal of Orthopsychiatry, 70*, 445-464

Didden, R. & Sigafoos, J. (2001). A review of the nature and treatment of sleep disorders in individuals with developmental disabilities. *Research in Developmental Disabilities, 22,* 255 – 272. doi: 10.1016/S0891-4222(01)00071-3

Disabled Living Foundation. (2016). *Key Facts: Families with disabled children*. Retrieved from: http://www.dlf.org.uk/content/key-facts

Doran, S. M., Harvey, M. T. & Horner, R. H. (2006). Sleep and developmental disabilities: Assessment, treatment and outcome measures. *Mental Retardation, 44*, 13 – 27.

Dyson, L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, functioning and social support. *American Journal on Mental Retardation, 102,* 267 – 279. doi: 10.1352/0895-8017(1997)102<0267:FAMOSC>2.0.CO;2)

Elliott, R., Fischer, C. & Rennie, D. (1999). Evolving Guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38,* 215 – 229.

Elmore, D. (2014). The impact of caregiving on physical and mental health: implications for research, practice, education and policy. In Talley, R. C., Fricchione, G. L. & Druss, B. G. (eds). *The Challenges of Mental Health Caregiving: Research, Practice, Policy*. USA: Springer

Emerson, E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge: Cambridge University Press.

Emerson, E. (2003). Prevalence of psychiatric disorders in child and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research, 47*, 51-58.

Eyberg, S. M., Nelson, M. M. & Boggs, S. R. (2008). Evidence-based psychosocial treatments for children and adolescents with disruptive behaviour. *Journal of Clinical Child and Adolescent Psychology, 37,* 215 – 237.

Fisher, P. & Goodley, D. (2007). The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. *Sociology of Health and Illness, 29*, 66 – 81. doi: 10.1111/j.1467-9566.2007.00518.x

Foster, R, H., Kozachek, S., Stern, M. & Elsea, S. H. (2010). Caring for the caregivers: An investigation of factors related to well-being among parents caring for a child with Smith-Magenis Syndrome. *Journal of Genetic Counseling, 19,* 187 – 198. doi: 10.1007/s10897-009-9273-5

Glaser, B. & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for qualitative research*. Chicago: Aldine.

Goldman, S. E., McGrew, S., Johnson, K. P., Richdale, A. L., Clemons, T. & Malow, B. A. (2011). Sleep is associated with problem behaviors in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*, 1223 – 1229.

Gregory, A. M. & O'Connor, T. G. (2002). Sleep problems in childhood: A longitudinal study of developmental change and association with behavioural problems. *Journal of the American Academy of Child and Adolescent Psychiatry, 41,* 964 – 972.

Greif, A. (1994). Cultural beliefs and the organisation of society: A historical and theoretical reflection on collectivist and individualist societies. *The Journal of Political Economy, 102,* 912 – 950.

Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18,* 59 – 82. doi: 10.1177/1525822X05279903

Hagan, T. & Smail, D. 1997a. Power-Mapping-I. Background and Basic Methodology. *Journal of Community and Applied Social Psychology, 7*, 257-267. doi: 10.1002/(SICI)1099-1298(199709)7:4<257::AID-CASP428>3.0.CO;2-P

Hinds, A. Elliott, A. & Vettini, A. (2001). *An Evaluation of a cognitive behavioural intervention provided by Sleep Scotland for families with children who have special needs and sleep problems.* Fife: Centre for Health and Social Research

HM Government (2015). *Parental Rights and Responsibilities*. Retrieved from: https://www.gov.uk/parental-rights-responsibilities/what-is-parental-responsibility

HM Treasury & Department for Education and Skills (2007a). *Aiming high for Disabled Children: Better support for families.* London: HM Stationery Office

HM Treasury & Department for Education and Skills (2007b). *Policy Review of Children and Young People – A discussion paper*. London: HM Stationery Office

Hodge, D., Hoffman, C. D., Sweeney, D. P. & Riggs, L. (2013). Relationship between children's sleep and mental health in mothers of children with and without Autism. *Journal of Autism and Developmental Disorders, 43,* 956 – 963. doi: 10.1007/s10803-012-1639-0

Hoffman, C. D., Sweeney, D. P., Gilliam, J. E. & Lopez-Wagner, M. C. (2006).

Sleep problems in children with autism and in typically developing children. *Focus on Autism and other Developmental Disabilities, 21,* 146 – 152.

Isa, S. N., Aziz, A. A., Rahman, A. A., Ibrahim, M. I., Ibrabim, W. P., Mohamad, N., et al. (2013). The impact of disabled children on parent health-related quality of life and family functioning in Kelantan and its associated factors. *Journal of Developmental and Behavioral Pediatrics, 34*, 262–268.

Jackson, J. (2011). *Gender Differences in Seeking Help*. Online Theses and Dissertations. Kentucky: Eastern Kentucky University

Jenson, S. Q. (2011). Othering, identity formation and agency. *Qualitative Studies, 2,* 63 – 78.

Kazdin, A. (2000). Treatment for aggressive and antisocial children. *Child and Adolescent Psychiatric Clinics of North America 9*, 841–858.

Keenan, R., Wild, M., McArthur, I. & Espie, C. (2007). Children with developmental disabilities and sleep problems: Parental beliefs and treatment acceptability. *Journal of Applied Research in Intellectual Disabilities, 20,* 455 – 465. doi: 10.1111/j.1468-3148.2007.00382.x

Khan, S. A., Heussler, H., McGuire, T., Dakin, C., Pache, D., Norris, R., Cooper, D. & Charles, B. (2011). Therapeutic options in the management of sleep disorders in visually impaired children: A systematic review. *Clinical Therapeutics, 33*, 168 – 181. doi: 10.1016/j.clinthera.2011.03.002

Knitzer, J. Theberge, S. & Johnson, K. (2008). *Reducing Maternal Depression and its Impact on Young Children: Toward a responsive early childhood policy framework.* USA: National Centre for Children in Poverty.

Konstantareas, M. M., Homatidis, S. & Plowright, C. M. (1992). Assessing

resources and stress in parents of severely dysfunctional children through the Clarke modification of Holroyd's Questionnaire on resources and stress. *Journal of Autism and Developmental Disorders, 22,* 217 – 234.

Kronk, R., Dahl, R. & Noll, R. (2009). Caregiver reports of sleep problems on a convenience sample of children with fragile X syndrome. *American Journal on Intellectual and Developmental Disabilities, 114,* 383 – 392. doi: 10.1352/1944-7588-114.6.383

Lee, J. (2013). Maternal stress, well-being and impaired sleep in mothers of children with developmental disabilities: A literature review. *Research in Developmental Disabilities, 34,* 4255 – 4273. doi: 10.1016/j.ridd.2013.09.008

Lerner, J. & Ashman, O. (2006). Culture and lifespan development. In K. Thies and J. F. Travers (2006). *Handbook of Human Development for Healthcare Professionals*. Sudbury: Jones and Bartlett Publishers.

Link, B. G. & Phelan, J. C. (2001). Conceptualising stigma. *Annual Review of Sociology, 27,* 363 – 385. doi: 10.1146/annurev.soc.27.1.363

Li-Tsang, C., Yau, M. & Yuen, H. (2001). Success in parenting children with developmental disabilities: Some characteristics, attitudes and adaptive coping skills. *The British Journal of Developmental Disabilities, 47*, 61 – 71.

Macdonald, G. & Williamson, E. (2002). *Against the Odds: An evaluation of child and family support services*. London: National Children's Bureau.

Markus, H. R. & Kitayama, S. (1991). Culture and the Self: Implications for cognition, emotion and motivation. *Psychological Review, 98,* 224 – 253.

Martz, E. (2001). Acceptance of imperfection. *Disability Studies Quarterly, 21,* 160 – 165.

McBride, B. (2009). *The Direct and Indirect Effects of Father Involvement on Maternal and Child Well-Being in Families of Children with Disabilities*. UK: MCH Research Final Report

McKay, M. M., Pennington, J., Lynn, C. & McCadam, K. (2001). Understanding urban child mental health service use: Two studies of child, family and environmental correlates. *Journal of Behavioural Health Services and Research, 28, 475 – 484.*

McLennan, J. D. & Kotelchuck, M. (2000) Parental prevention practices for young children in the context of maternal depression. *Paediatrics, 105*, 1090 - 1095. doi:10.1542/peds.105.5.1090

Miller, G. E. & Prinz, R. J. (2003). Engagement of families in treatment for childhood conduct problems. *Behaviour Therapy, 34,* 517 – 534.

Miller, A. C., Gordon, R. M., Daniele, R. J., & Diller, L. (1992). Stress, appraisal, and coping in mothers of disabled and nondisabled children. *Journal of Pediatric Psychology, 17*, 587 – 605. doi:10.5463/DCID.v23i2.119

Minde, K., Faucon, A. & Falkner, S. (1994), Sleep problems in toddlers: Effects of treatment on their daytime behaviour. *Journal of the American Academy of Child and Adolescent Psychiatry, 33,* 1114 – 1121.

Mindell, J. (1997). Children and sleep. In Pressman, M. & Orr, W (eds) *The Evaluation and Treatment of Sleep Disorders: Application and Practice in Health Psychology*. Washington DC: American Psychological Association

Mindell, J. & Durand, M. (1993). Treatment of childhood sleep disorders: generalization across disorders and effects on family members. *Journal of Paediatric Psychology, 18, 731 – 750.*

Mindell, J. A., Kuhn, B., Lewis, D. S., Meltzer, L. J. & Sadeh, A. (2006).

Behavioural treatment of bedtime problems and night wakings in infants and young children. *Sleep, 29,* 1263 – 1279.

Mindell, J. Sadeh, A, Wiegand, B. How, T. H. & Goh, D. Y. T. (2010). Cross-cultural differences in infant and toddler sleep. *Sleep Medicine, 11,* 274 – 280.

Montgomery, P., Stores, G. & Wiggs, L. (2004). The relative efficacy of two brief treatments for sleep problems in young learning disabled (mentally retarted) children: a randomized controlled trial. *Archives of Disease in Childhood, 89,* 125 – 130. doi: 10.1136/adc.2002.017202

Montgomery, P. & Wiggs, L. (2007). *Encouraging Good Sleep Habits in Children with Learning Disabilities*. UK: Research Autism

Mooney, A., Owen, C. & Statham, J. (2007). *A National Disabled Children's Indicator – Using a Survey of Parents: A Feasibility Study*. Report to Department for Children, Schools and Families

Mooney, A., Owen, C. & Statham, J. (2008). *Disabled children: Numbers, Characteristics and Local Service Provision*. London: HM Stationery Office

Morawska, A., Ramadewi, M. D. & Sanders, M. (2014). Using epidemiological survey data to examine factors influencing participation in parent-training programmes. *Journal of Early Childhood Research, 12,* 264 – 278. doi: 10.1177/1476718X14536952

Morrell, J. (1999). The role of maternal cognitions in infant sleep problems as assessed by a new instrument, the maternal cognitions about infant sleep questionnaire. *Journal of Child Psychology and Psychiatry, 40,* 247 – 258. doi: 10.1111/1469-7610.00438

Morrissey-Kane, E. & Prinz, R. (1999). Engagement in child and adolescent

treatment: The role of parental cognitions and attributions. *Clinical Child and Family Psychology Review, 2,* 183 – 198. doi: 1096-4037/99/0900-0183

Nadler, A., Lewinstein, E. & Rahav, G. (1991). Acceptance of mental retardation and help-seeking by mothers and fathers of children with mental retardation. *Mental Retardation, 29,* 17 – 23.

NHS Constitution for England. (2013). London: Department of Heath

NICE (2015). *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*. NICE Guideline. Retrieved from: https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-1837266392005

Office for Disability Issues & Department of Work and Pensions (2014). *Disability prevalence estimates 2002/03 to 2011/12 (Apr to Mar)*. Retrieved from: https://www.gov.uk/government/statistics/disability-prevalence-estimates-200203-to-201112-apr-to-mar

Ostberg, M., Hagekull, B., Lindberg, L. & Dannaeus, M. (2005). Can a child-focused intervention reduce mothers' stress? *Parenting: Science and Practice, 5,* 153 – 174. doi: 10.1207/s15327922par0502_2

Paavonen, E. J., Almqvist, F., Tamminen, T., Moilanen, J., Piha, J., Rasanen, E. & Aronen, E. T. (2002). Poor sleep and psychiatric symptoms at school: An epidemiological study. *European Child and Adolescent Psychiatry, 11,* 10 – 17.

Pastor, A., Brandwein, D. & Walsh, J. (2009). A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research in Developmental Disabilities, 30,* 1337 – 1342. doi: 10.1016/j.ridd.2009.05.010

Patton, M. (2015). *Qualitative Evaluation and Research Methods: Integrating Theory and Practice, 4th edition*. USA: Sage

Patzold, L., Richdale, A. & Tonge, B. (1998). An investigation into sleep characteristics of children with Autism and Asperger's Disorder. *Journal of Paediatrics and Child Health, 3,* 528 – 533.

Pavuluri, M. N., Luk, S. & McGee, R. (1996). Help-seeking for behaviour problems by parents of pre-school children: A community study. *Journal of the American Academy of Child and Adolescent Psychiatry, 35,* 215 – 222.

Peckover, S. (2002). Supporting and policing mothers: An analysis of the disciplinary practices of health visiting. *Journal of Advanced Nursing, 38,* 369 – 377. doi: 10.1046/j.1365-2648.2002.02197.x

Pilgrim, D. & Rogers, A. (1997) The contribution of lay knowledge to the understanding and promotion of mental health. *Journal of Mental Health, 6,* 23 -35

Pilgrim, D. & Bentall, R. (1999). The medicalisation of misery: A critical realist analysis of the concept of depression. *Journal of Mental Health, 8,* 261 – 274.

Pisula, E. & Kossakowska, Z. (2010). Sense of coherence and coping with stress among mothers and fathers of children with autism. *Journal of Autism and Developmental Disorders, 40,* 1485 – 1494. doi: 10.1007/s10803-010-1001-3

Polimeni, M. A., Richdale, A. L. & Francis, J. P. (2005). A survey of sleep problems in Autism, Asperger's Disorder and typically developing children. *Journal of Intellectual Disability Research, 49,* 260 – 268

Polimeni, M., Richdale, A. & Francis, A. (2007). The impact of children's sleep

problems on the family and behavioural processes related to their development and maintenance. *E-Journal of Applied Psychology, 3*, 76 – 85

Prime Ministers Strategy Unit, (2005). *Improving the Life Chances of Disabled People*. London: HM Stationery Office

Quine, L. (1991). Sleep problems in children with mental handicap. *Journal of Mental Deficiency Research, 35,* 269 – 290.

Quine, L. (1992). Severity of sleep problems in children with severe learning difficulties: description and correlates. *Journal of Community and Applied Psychology, 2,* 247 – 268. doi: 1052-9284/92/040247-22

Quine, L. (2001). Sleep problems in primary school children: comparison between mainstream and special school children. *Child: Care, Health and Development, 27,* 201 – 221.

Reder, P. & Fredman, G. (1996). The Relationship to Help: Interacting beliefs about the treatment process. *Clinical Child Psychology and Psychiatry, 1,* 457 – 467.

Reimers, T., Wacker, D., Derby, K. & Cooper, L. (1995). Relation between parental attributions and the acceptability of behaviour treatments for their child's behaviour problems. *Behaviour Disorders, 20,* 581 – 590.

Reiter-Purtill, J., Schorry, E. K., Lovell, A. M., Vannatta, K., Gerhardt, C. A. & Noll, R. B. (2008). Parental distress, family functioning and social support in families with and without a child with Neurofibromatosis. *Journal of Pediatric Psychology, 33,* 422 – 434. doi: 10.1093/jpepsy/jsm077

Richdale, A. (1999). Sleep problems in Autism: prevalence, cause and intervention. *Developmental Medicine and Child Neurology, 41,* 60 – 66.

Richdale, A. (2001). Sleep disorders in Autism and Asperger's Syndrome. In

G. Stores & L. Wiggs (Eds.), *Sleep Disturbance in Children and Adolescents with Disorders of Development: Its Significance and Management* (pp 181 – 191). London: Mac Keith Press

Richdale, A., Gavidia-Payne, S., Francis, A. & Cotton, S. (2000). Stress, behaviour and sleep problems in children with an intellectual disability. *Journal of Intellectual and Developmental Disability, 25,* 147 – 161. doi: 10.1080/13269780050033562

Richdale, A. & Wiggs, L. (2005). Behavioural Approaches to the treatment of sleep problems in children with developmental disorders: What is the state of the art? *International Journal of Behavioural and Consultation Therapy, 1,* 165 – 190. ISSN: ISSN-1555-7855

Richdale, A. L. (2013). Autism and other developmental disabilities. In A. R. Wolfson & H. Montgomery-Downs (Eds). *The Oxford Handbook of Infant, Child, and Adolescent Sleep: Development and behaviour* (pp. 471–94). Oxford: Oxford University Press.

Richdale, A. & Baker, E. (2014). Sleep in individuals with an intellectual or developmental disability: Recent research reports. *Current Developmental Disorders Reports, 1*, 74 – 85. doi: 10.1007/s40474-014-0010-x

Richman, N., Douglas, J., Hunt, H., Lansdown, R., & Levere, R. (1985). Behavioural methods in the treatment of sleep problems—a pilot study. *Journal of Child Psychology and Psychiatry, 26*, 581–590. doi: 10.1111/j.1469-7610.1985.tb01642.x

Robinson, A. M. & Richdale, A. L. (2004). Sleep problems in children with an intellectual disability: parental perceptions of sleep problems, and views of treatment effectiveness. *Child: Care, health and development, 30,* 139 – 150.

Rogers, J. (2005). *The Disabled Woman's Guide to Pregnancy and Birth*. New

York: Demos Medical Publishing

Rogers, M., L. & Hogan, D. P. (2003). Family life with children with disabilities: The key role of rehabilitation. *Journal of Marriage and Family, 65,* 818 – 833. doi: 10.1111/j.1741-3737.2003.00818.x

Rooke, O., Thompson, M. & Day, C. (2004). School-based open access parenting programmes: Factors relating to uptake. *Child and Adolescent Mental Health, 9,* 130 – 138.

Rossiter, L. & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantative integration of the literature. *Journal of Child and Family Studies, 10,* 65 - 84.

Sadeh, A., Gruber, R. & Raviv, A. (2002). Sleep, neurobehavioural functioning and behaviour problems in school-age children. *Child Development, 73,* 405 – 417.

Sadeh, A., Mindell, J. A. & Owens, J. (2011). Why care about sleep of infants and their parents? *Sleep Medicine Reviews, 15,* 335 – 337.

Sadeh, A., Mindell, J. & Rivera, L. (2011). “My child has a sleep problem”: A cross-cultural comparison of parental definitions. *Sleep Medicine, 12,* 478 – 482. doi: 10.1016/j.sleep.2010.10.008

Sakaguchi, M., & Beppu, S. (2007). Structure of stressors in mothers of preschool children with autism. *Japanese Journal of Special Education, 45*, 127 – 136.

Samuel, P. (2007). *Psychometric evaluation of the Family Quality of Life Survey for low-income minority families*. Research proposal submitted to the National Institute on Disability Research and Rehabilitation: CFDA. Detroit: Wayne State University.

Samuel, P. S., Rillotta, F., & Brown, I. (2012). The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research, 56*, 1–16. http://dx.doi.org/10.1111/j.1365-2788.2011.01486.x

Shakespeare, T. (2013). The social model of disability. In L, Davies (2013). *The Disabilities Studies Reader* (4th edition). New York: Routledge

Sheldon, S. H. (2001). Insomnia in Children. *Current Treatment Options in Neurology, 3,* 37 – 50.

Smith, T. B., Oliver, M. N. & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry, 71,* 257 – 261. doi: 10.1037/0002-9432.71.2.257

Smith, J., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, method and research*. London: Sage.

Sorin, R. (2005). Changing images of childhood: Reconceptualising early childhood practice. *International Journal of Transitions in Childhood, 1,* 12 – 21.

Spoth, R., Redmond, C. & Shin, C. (2000). Modeling factors influencing enrollment in family-focused preventive intervention research. *Prevention Sciences, 1,* 213 – 225.

Stone, S. D. (1995). The myth of bodily perfection. *Disability and Society, 10,* 413 – 424. doi: 10.1080/09687599550023426

Stores, G. (2001). *A Clinical Guide to Sleep Disorders in Children and Adolescents*. Cambridge: Cambridge University Press.

Stores, G. (2002). Annotation: children's sleep disorders: Modern approaches, developmental effects, and children at special risk. *Developmental*

Medicine and Child Neurology, 41, 568 – 73.

Tamis-LeMonda, C. S., Way, N., Hughes, D., Yoshikawa, H., Kalman, R. K. & Niwa, E. Y. (2008). Parents' goals for children: The dynamic coexistence of individualism and collectivism in cultures and individuals. *Social Development, 17,* 183 – 209. doi: 10.1111/j.1467-9507.2007.00419.x

Taleporos, G. & McCabe, M. P. (2002). Body image and physical disability – personal perspectives. *Social Sciences & Medicine, 54,* 971 – 980. doi: 10.1016/S0277-9536(01)00069-7

Taylor, G. & Ussher, J. (2001). Making sense of S&M: A discourse analytic account. *Sexualities, 4,* 293 – 314.

Taylor, M. A., Schreck, K. A. & Mulick, J. A. (2012). Sleep disruption as a correlate to cognitive and adaptive behavior problems in autism spectrum disorders. *Research in Developmental Disabilities, 33*, 1408 – 1417.

Thurer, S. (1995). *Myths of Motherhood: How culture reinvents the good mother.* New York: Penguin Books

Tietze, A. L., Blankenburg, M., Hechler, T., Michel, E., Koh, M., Schluter, B. & Zernikow, B. (2012). Sleep disturbances in children with multiple disabilities. *Sleep Medicine Reviews, 16*, 117– 27. doi: 10.1016/j.smrv.2011.03.006

Timimi, S. (2014). No more psychiatric labels: Why formal psychiatric diagnostic systems should be abolished. *International Journal of Clinical and Health Psychology, 14,* 208 – 215. doi: 10.1016/j.ijchp.2014.03.004

Todd, S. & Jones, S. (2003). 'Mum's the Word!': Maternal accounts of dealings with the professional world. *Journal of Applied Research in Intellectual Disabilities, 16,* 229 – 244. doi:10.1046/j.1468-3148.2003.00163.x

Turnbull, A. P., Turnbull, H. R., Poston, D., Beegle, G., Blue-Banning M. et al. (2004). Enhancing quality of life of families of children and youth with developmental disabilities in the United States. In A. Turnbull, A. P., Brown, I & Turnbull, H. R. (2004) (eds). *Families and People with Mental Retardation and Quality of Life: International perspectives*. Washington DC: American Association on Mental Retardation.

Union of the Physically Impaired Against Segregation (1976). *Fundamental Principles of Disability*. Retrieved from: http://en.wikipedia.org/wiki/Union_of_the_Physically_Impaired_Against_Segregation

United Nations (2006). *Convention of the Rights of Persons with Disabilities*. Retrieved from: http://www.un.org/disabilities/convention/about.shtml

Wiggs, L. (2001). Sleep problems in children with developmental disorders. *Journal of the Royal Society of Medicine, 94,* 177 – 179.

Wiggs, L. & France, K. (2000). Behavioural treatments for sleep problems in children and adolescents with physical illness, psychological problems or intellectual disabilities. *Sleep Medicine Reviews, 4,* 299 – 314.

Wiggs, L. & Stores, G. (1996). Sleep problems in children with severe intellectual disabilities: What help is being provided? *Journal of Applied Research in Intellectual Disabilities, 9,* 159 – 164. doi: 1360-2322/96/020159-6

Wiggs, L. & Stores, G. (1998). Factors affecting parental reports of the sleep patterns of children with severe learning disabilities. *British Journal of Health Psychology, 3,* 345 -259. doi: 10.1111/j.2044-8287.1998.tb00579.x

Wilkinson, R. & Pickett, K. (2009). *The Spirit Level: Why More Equal Societies Almost Always Do Better*. London: Allen Lane

Williams, J. (2006). How social myths about childhood, motherhood and medicine affect the detection of subtle developmental problems in young children. *Contemporary Nurse, 23,* 274 – 287.

Willig, C. (2013). *Introducing Qualitative Research in Psychology*. Berkshire: Open University Press.

Winnicott, D. W. (1949). The ordinary devoted mother. In C. Winnicott, R. Shepherd & M. Davies (eds) *Babies and their Mothers.* USA: Addison-Wesley Publishing Company Inc.

APPENDIX A: Table 1: Literature search

Search Terms	Number of searches returned	Academic Search Complete	PsychINFO	CINAHL Plus	Child Development and Adolescent studies	PsychARTICLES	When limited by age (or subject term: */**), number of searches returned	Number of relevant searches returned
carers or caregivers or family members or guardians or keeper AND disabilities AND sleep	255	101	86	62	4	2	66	38
carers or caregivers or family members or guardians or keeper AND impairments AND sleep	284	102	119	61	1	1	35	15
carers or caregivers or family members or guardians or keeper AND retardation AND sleep	61	22	35	4	0	0	24	11
Parents AND disabilities AND	470	181	176	85	26	2	217	100

sleep								
Parents AND impairments AND sleep	231	94	93	34	8	2	106	40
Parents AND retardation AND sleep	126	37	70	10	9	0	68	32
Parents AND carers or caregivers or family members or guardians or keeper AND help-seeking	207	59	87	48	9	4	*36	9
Parents AND carers or caregivers or family members or guardians or keeper AND relationship to help	228	61	115	32	18	2	**130	8
Relationship to help AND disabilities AND sleep	3	1	1	1	0	0	N/A	2
Relationship to help AND disabilities	474	197	176	78	17	6	70	8
Relationship to help AND sleep	135	45	56	29	1	4	19	1
Help seeking AND	13	7	3	3	0	0	N/A	1

disabilities AND sleep								
Help seeking AND disabilities	732	278	262	166	12	14	78	10
Help seeking AND sleep	196	75	67	48	6	0	27	6

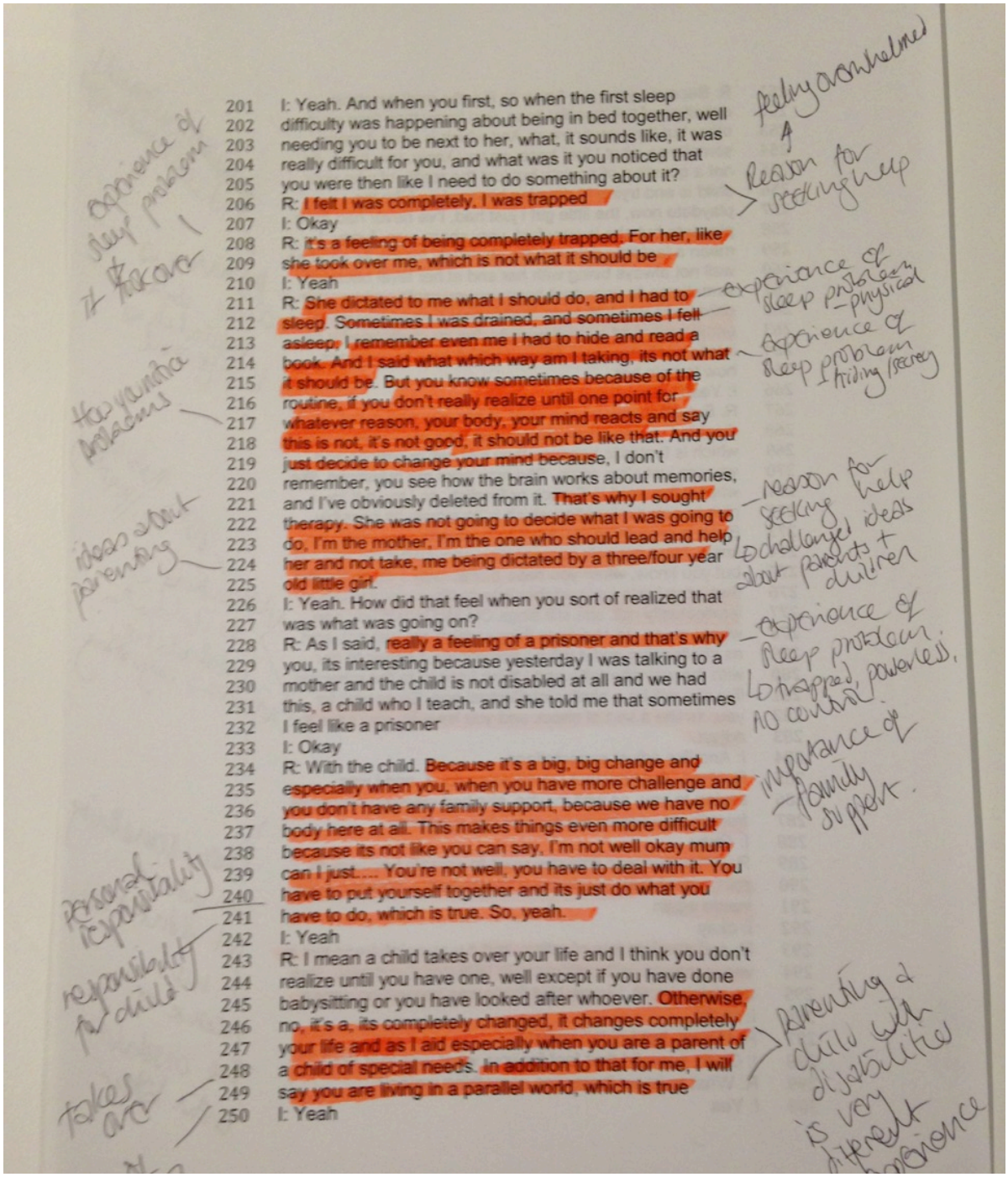
*** Narrow by Subject:**

children
adaptability (psychology)
children -- conduct of life
family relations
qualitative research
research – methodology
child rearing
stress (psychology)
child care
families
parents
parent & child
child development
social support
adolescence
adjustment (psychology)
parents – attitudes
caregivers
burden of care
patients' families
parenting
thematic analysis
interviewing
help-seeking behavior

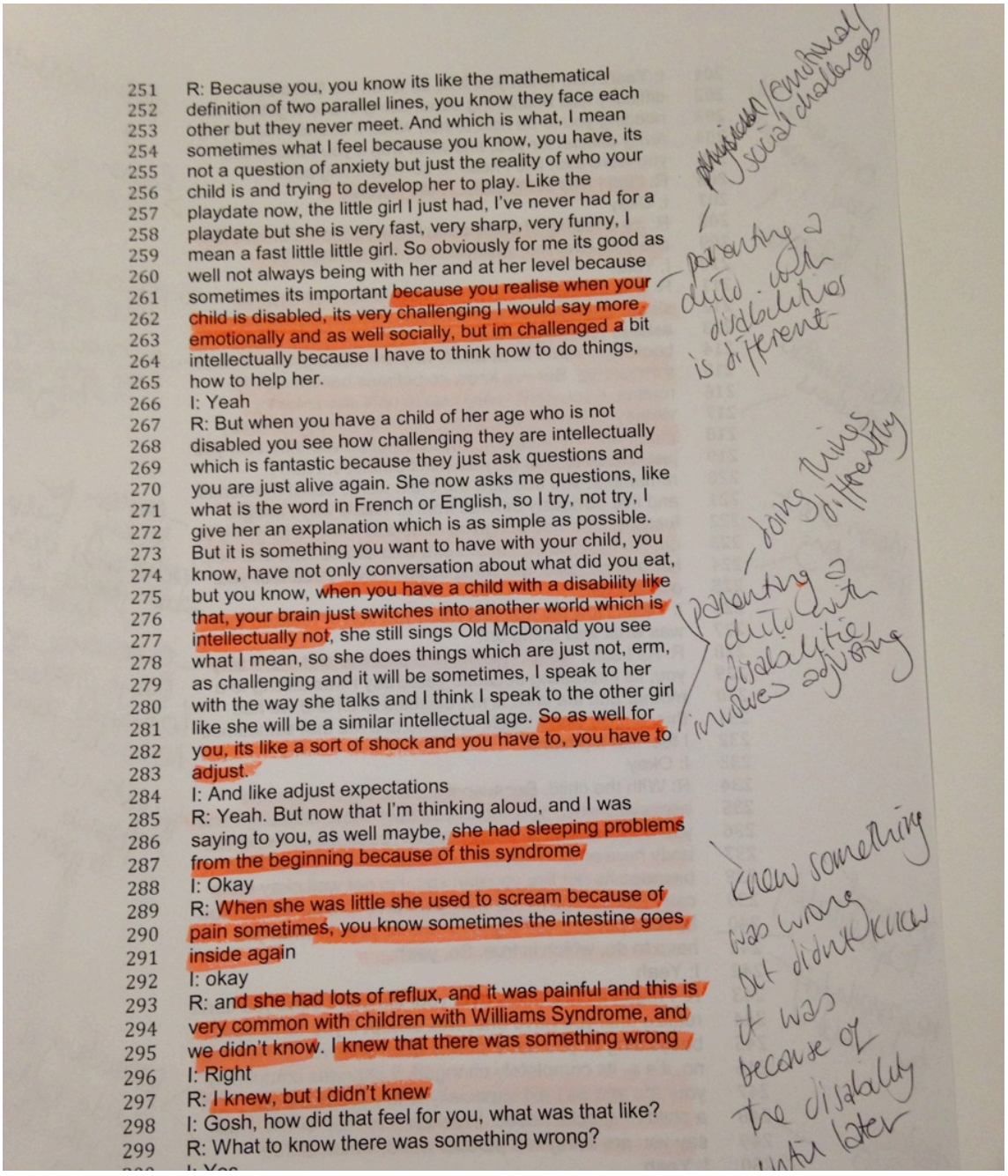
**** Narrow by Subject:**

psychotherapeutic techniques
parent-child relations
family members
sibling relations
caregiver burden
health care services
intervention
family relations
caregivers
psychotherapeutic processes
interpersonal relationships
coping behavior
parental attitudes
parents
emotional responses
health care utilization
parent child relations
mothers
siblings
child care
crises
disabilities
mental health
problem solving
attachment behavior
parenting style
mother child relations
parenting
adaptation, psychological
child welfare
daughters
marital relations
pediatrics
family
parenting skills

APPENDIX B: Example of Annotated Transcript



I: Yeah. And when you first, so when the first sleep difficulty was happening about being in bed together, well needing you to be next to her, what, it sounds like, it was really difficult for you, and what was it you noticed that you were then like I need to do something about it?
R: I felt I was completely, I was trapped
I: Okay
R: It's a feeling of being completely trapped. For her, like she took over me, which is not what it should be
I: Yeah
R: She dictated to me what I should do, and I had to sleep. Sometimes I was drained, and sometimes I fell asleep. I remember even me I had to hide and read a book. And I said what which way am I taking, its not what it should be. But you know sometimes because of the routine, if you don't really realize until one point for whatever reason, your body, your mind reacts and say this is not, it's not good, it should not be like that. And you just decide to change your mind because, I don't remember, you see how the brain works about memories, and I've obviously deleted from it. That's why I sought therapy. She was not going to decide what I was going to do, I'm the mother, I'm the one who should lead and help her and not take, me being dictated by a three/four year old little girl.
I: Yeah. How did that feel when you sort of realized that was what was going on?
R: As I said, really a feeling of a prisoner and that's why you, its interesting because yesterday I was talking to a mother and the child is not disabled at all and we had this, a child who I teach, and she told me that sometimes I feel like a prisoner
I: Okay
R: With the child. Because it's a big, big change and especially when you, when you have more challenge and you don't have any family support, because we have no body here at all. This makes things even more difficult because its not like you can say, I'm not well okay mum can I just.... You're not well, you have to deal with it. You have to put yourself together and its just do what you have to do, which is true. So, yeah.
I: Yeah
R: I mean a child takes over your life and I think you don't realize until you have one, well except if you have done babysitting or you have looked after whoever. Otherwise, no, it's a, its completely changed, it changes completely your life and as I aid especially when you are a parent of a child of special needs. In addition to that for me, I will say you are living in a parallel world, which is true
I: Yeah



R: Because you, you know its like the mathematical definition of two parallel lines, you know they face each other but they never meet. And which is what, I mean sometimes what I feel because you know, you have, its not a question of anxiety but just the reality of who your child is and trying to develop her to play. Like the playdate now, the little girl I just had, I've never had for a playdate but she is very fast, very sharp, very funny, I mean a fast little little girl. So obviously for me its good as well not always being with her and at her level because sometimes its important because you realise when your child is disabled, its very challenging I would say more emotionally and as well socially, but im challenged a bit intellectually because I have to think how to do things, how to help her.

I: Yeah

R: But when you have a child of her age who is not disabled you see how challenging they are intellectually which is fantastic because they just ask questions and you are just alive again. She now asks me questions, like what is the word in French or English, so I try, not try, I give her an explanation which is as simple as possible. But it is something you want to have with your child, you know, have not only conversation about what did you eat, but you know, when you have a child with a disability like that, your brain just switches into another world which is intellectually not, she still sings Old McDonald you see what I mean, so she does things which are just not, erm, as challenging and it will be sometimes, I speak to her with the way she talks and I think I speak to the other girl like she will be a similar intellectual age. So as well for you, its like a sort of shock and you have to, you have to adjust.

I: And like adjust expectations

R: Yeah. But now that I'm thinking aloud, and I was saying to you, as well maybe, she had sleeping problems from the beginning because of this syndrome

I: Okay

R: When she was little she used to scream because of pain sometimes, you know sometimes the intestine goes inside again

I: okay

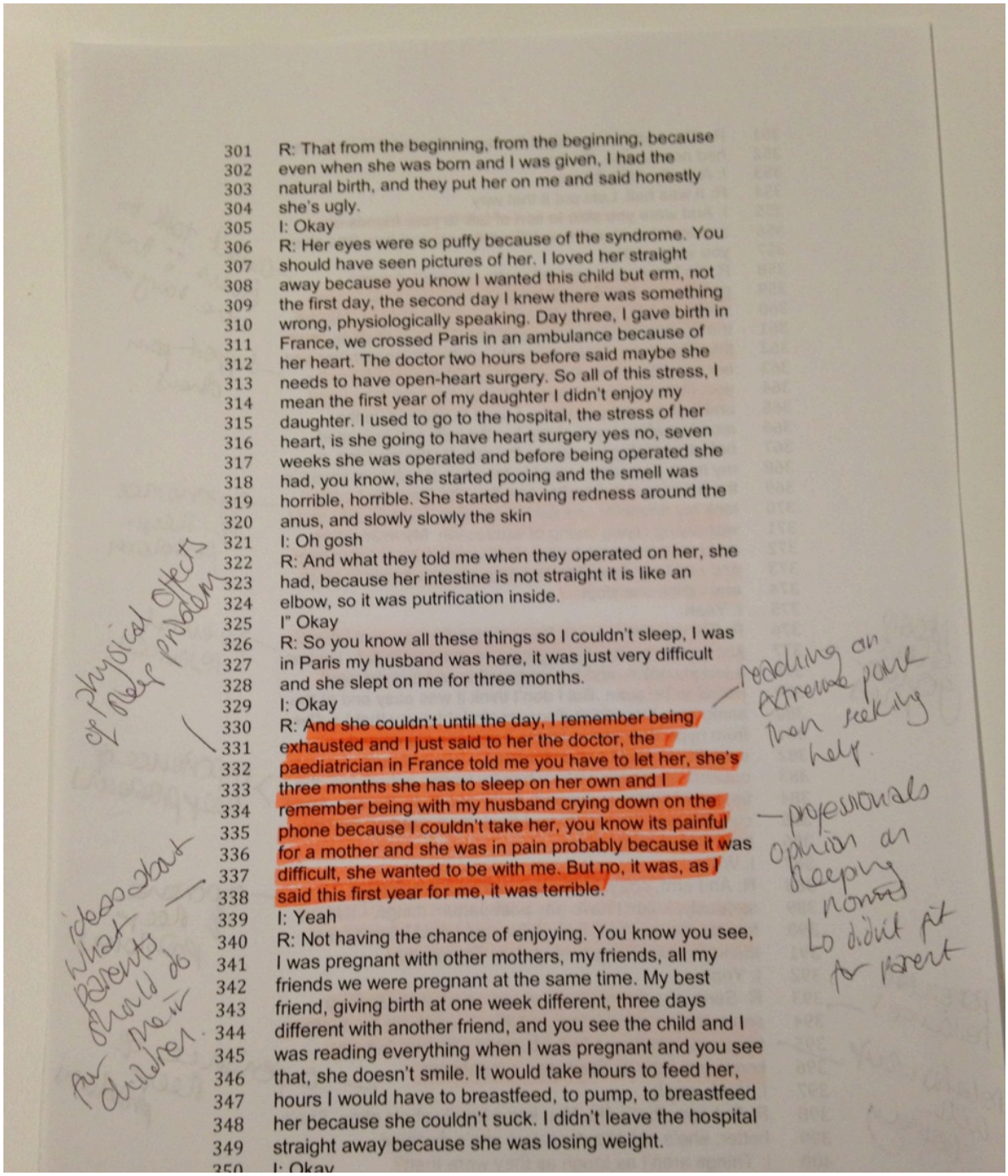
R: and she had lots of reflux, and it was painful and this is very common with children with Williams Syndrome, and we didn't know. I knew that there was something wrong

I: Right

R: I knew, but I didn't knew

I: Gosh, how did that feel for you, what was that like?

R: What to know there was something wrong?



R: That from the beginning, from the beginning, because even when she was born and I was given, I had the natural birth, and they put her on me and said honestly she's ugly.
I: Okay
R: Her eyes were so puffy because of the syndrome. You should have seen pictures of her. I loved her straight away because you know I wanted this child but erm, not the first day, the second day I knew there was something wrong, physiologically speaking. Day three, I gave birth in France, we crossed Paris in an ambulance because of her heart. The doctor two hours before said maybe she needs to have open-heart surgery. So all of this stress, I mean the first year of my daughter I didn't enjoy my daughter. I used to go to the hospital, the stress of her heart, is she going to have heart surgery yes no, seven weeks she was operated and before being operated she had, you know, she started pooing and the smell was horrible, horrible. She started having redness around the anus, and slowly slowly the skin
I: Oh gosh
R: And what they told me when they operated on her, she had, because her intestine is not straight it is like an elbow, so it was putrification inside.
I" Okay
R: So you know all these things so I couldn't sleep, I was in Paris my husband was here, it was just very difficult and she slept on me for three months.
I: Okay
R: And she couldn't until the day, I remember being exhausted and I just said to her the doctor, the paediatrician in France told me you have to let her, she's three months she has to sleep on her own and I remember being with my husband crying down on the phone because I couldn't take her, you know its painful for a mother and she was in pain probably because it was difficult, she wanted to be with me. But no, it was, as I said this first year for me, it was terrible.
I: Yeah
R: Not having the chance of enjoying. You know you see, I was pregnant with other mothers, my friends, all my friends we were pregnant at the same time. My best friend, giving birth at one week different, three days different with another friend, and you see the child and I was reading everything when I was pregnant and you see that, she doesn't smile. It would take hours to feed her, hours I would have to breastfeed, to pump, to breastfeed her because she couldn't suck. I didn't leave the hospital straight away because she was losing weight.
I: Okay

APPENDIX C: Excerpt from Table of Codes, with Line Numbers from Interviews

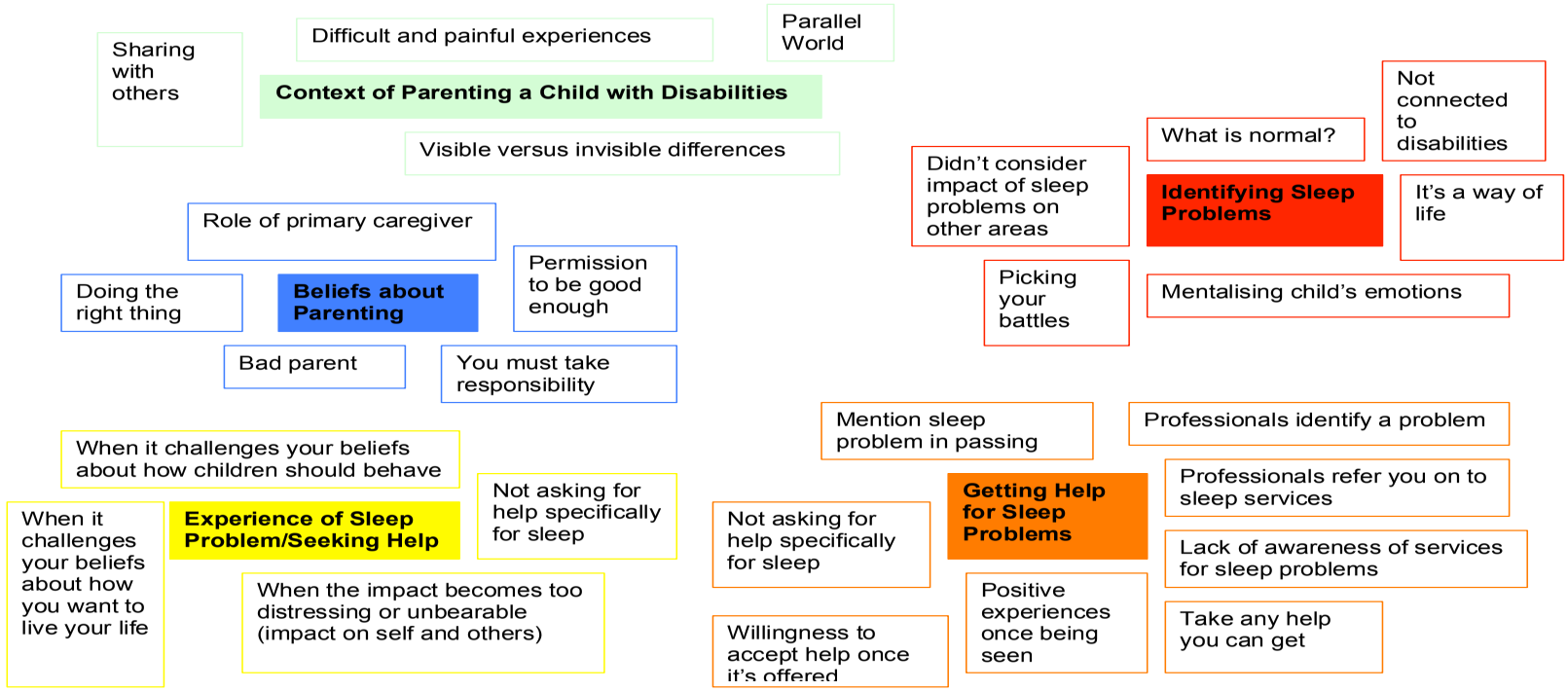
	Interview 1	Interview 2	Interview 3	Interview 4	Interview 5	Interview 6	Interview 7	Interview 8	Interview 9
How babies and/or children should be	195: boys will be boys, normal it's a boy					51: textbook baby 397: boys will be boys - minimised mum's concerns			
Talking to others	447: not something I am sharing 452: there is a point you realise you are in a parallel universe to other parents, even though you started the same, it is so different	495: no one realises how bad he is until you live with us 498: sister's think I talk a load of rubbish				52: Didn't want to boast, couldn't tell other mums 369: people don't embrace difference	264: it's hard to discuss things in Asian countries – expectations are different 435: talking to mum's in Singapore about it, felt very blamed, worst parent. Stopped her from sharing anymore, felt isolated	110: talking and sharing with others who are in a similar position is the best way to get tips 358: couldn't talk to friends or family about little sleep because their children were sleeping well and they couldn't offer any help 617: because of the	697: only spoke to wife's aunt about it, because she was a nurse

								tiredness and the stress I don't call because I don't have the time, and you don't want to put pressure or stress on them	
Reasons for seeking help, attending, taking, following advice	342: asking for individual tailored help as still worried about danger and still had to be with him all of the time 363: takes time to process diagnosis and realise you do need extra help 365: you better use whatever help you can	45: took him to the GP because I couldn't cope 421: went to the chemist 621: the process was hard, and upsetting – but didn't want to let people down	588: sleep problems we shared because we had to, because I thought it might help and it did help because they give me melatonin	170: sought help because it was affecting mum's well-being, ability to study	232, 241: already attending a group where problems are shared and discussed regularly	201: when professionals told me about it 206: willing to try anything 217: getting help and finding out about stuff 320: doing own research 360: didn't want another thing to do (weighted blanket)			117: worried about the neighbours so trying to keep him quiet 289: it got to the stage where I realised I don't know if I can actually keep going like this, it as like torture, it was most difficult period of my life besides getting the diagnosis of autism 614: but we were happy

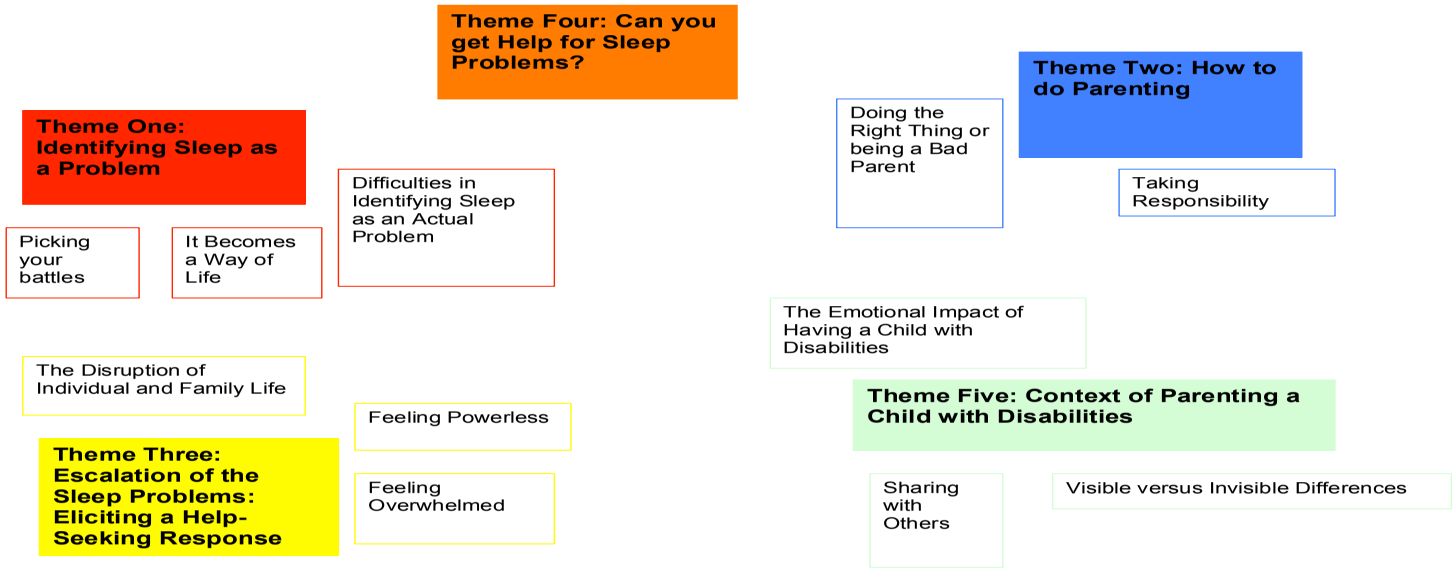
									with anything. It was really that stage of level, I won't lie to you, I don't know what we would have done, it's like totally hopeless
How you notice sleep problems		263: when you start catching up on your sleep 343: just thought the doctor could give me something quickly		157: picking your battles and sweating the small stuff			225: I knew right from the beginning 548: son recognised a problem himself 597: what is identified as a problem – co-sleeping for this family was very normal. 684: Husband noticed when he couldn't go to normal school	215: you know sometimes because of the routine you don't realise, until one point your body/mind reacts and it's not good 286: she had sleeping problems from the beginning because of this syndrome but we didn't know it was common, but did know	

								something was wrong	
Sleep is not the primary concern			424: saw someone at CAMHS for something else, and then she mentioned about referring on					438: so as a parent it's painful. You can't fight for everything, I have to give priority to what is important	
Minimising effects of sleep difficulties **Not prioritising sleep, other issues are more important**	300: I don't know if I asked that loudly 300: save the boy, help him cope in the world, sleep was number 5 on priority list	218, 227: didn't pay it much attention because of everything else 260: weren't really interested in the sleep thing then			208: issue was always there but not as bad as last two years	393: didn't give it the impact 394: flippant about it			109: while we thought yeah that's awful, that's not too bad. Then in six months things changed quite badly 295: besides finding out he was autistic, that was the biggest bombshell that's ever happened to me

APPENDIX D : Initial Theme Map: Colour-coded by Theme and Positioned in Relation to Each Other, with clusters of codes.



APPENDIX E: Final Thematic Map



APPENDIX F: Interview Schedule

Central and North West London NHS
NHS Foundation Trust

University of East London
School of Psychology
Stratford Campus
Water Lane, Stratford
London, E15 4LZ

INTERVIEW SCHEDULE

Introductions and Engagement

Verbal reminder of consent, confidentiality and that the participant may withdraw at any time. Agree approximate length of interview and give a brief reminder of what the interview is about.

Questions

Because this is an interview about being a parent, I'd like to start by asking you about your children:

- How many do you have?
- Names and ages?
- Do they live with you? If not, how often do you see them?
- How many of your children have disabilities?
- How many of your children have sleep problems?
- What are the sleep problems you/your child experience?
- How have the sleep problems fluctuated over time?

Tell me about your child's sleep problem. What has it been like for you as a parent?

How have you responded as a parent to your child and his/her sleep problem?

Tell me about your child's sleep difficulties in relation to other difficulties they may have?

- Has one had more or less of an effect than others?

How did sleep difficulties become identified as a problem?

- Who first became concerned
- What were the concerns?
- How did you see your role/your co-parents role in managing this?
- Whose decision was it to seek extra support/access the sleep service?
- How did you experience that? Was it useful?
- How does seeking help for sleep differ from seeking other types of help?

How have the people you and your child live with responded to the sleep difficulties?

- Has it been a problem for them?
- Has it affected your relationship with them?
- Has it affected the relationship between them and your child with disabilities and sleep problems?
- How have they responded practically?

How have other family members, friends, other parents responded to the sleep difficulties?

- Has it been a problem for them
- Has it affected your relationship with them
- Has it affected the relationship between them and your child with disabilities and sleep problems?
- How have they responded practically?

Ending

Is there anything else that you would like to share with me, or anything important that I haven't asked?

Debriefing

How do you feel about the conversation we just had? Do you have any questions about what we have just discussed? Is there anything that concerns or bothers you? Is there anything you would like me to leave out? If you think of any other questions later, please do contact me. Here are the details of other support organisations that you can contact if you feel like you'd like to talk to someone.

APPENDIX G: Invitation to Participate

Central and North West London NHS
NHS Foundation Trust

University of East London
School of Psychology
Stratford Campus
Water Lane, Stratford
London, E15 4LZ

Dear……..

I am writing this letter to invite you to participate in a research study called **'Parents of Children with Disabilities: Exploring the reasons for seeking help for sleep difficulties'**

The purpose of this research project is to find out about the parenting experiences of parents of children with disabilities and the reasons they seek help and support for their child/children's sleep difficulties.

The research involves being interviewed for between 45 minutes to an hour. During this time, you will be asked questions about being a parent of a child with disabilities and sleep difficulties and what it has been like to seek help for your child/children. There will be time at the end for you to ask the researcher any questions, or to say anything that they didn't ask about.

There are not any specific treatment benefits from participating in this study. However, there may be some indirect benefits in the form of making services more accessible and useful to parents of children with disabilities who also experience sleep difficulties, and help services know how to better support parents in similar situations in the future.

If you would like to participate please contact the Chief Investigator using the details below, or contact the sleep service at MOSAIC.

Thank you in anticipation.

Yours sincerely,

Annie McHugh

Chief Investigator/Trainee Clinical Psychologist
University of East London
u1331801@uel.ac.uk

Dr. Susan Cottam

Clinical Psychologist
MOSAIC
020 3317 2261

APPENDIX H: Participant Information Sheet

Central and North West London NHS
NHS Foundation Trust

University of East London
School of Psychology
Stratford Campus
Water Lane, Stratford
London, E15 4LZ

PARTICIPANT INFORMATION SHEET

Chief Investigator: Annie McHugh (U1331801@uel.ac.uk)

Study title

Parents of Children with Disabilities: Exploring the reasons for seeking help for sleep difficulties.

Invitation and brief summary

I would like to invite you to take part in my research study, which is part of my doctoral thesis. Joining the study is entirely up to you, before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. I would suggest this should take about 5 minutes. Please feel free to talk to others about the study if you wish.

The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part.

Then I will give you more detailed information about the conduct of the study.

Do ask if anything is unclear.

What's involved?

Children with disabilities are likely to experience sleep difficulties that can affect their behaviour and their physical and emotional well-being. These sleep difficulties can also have huge impacts on their parents and other family members, including increased stress, distress and difficulties coping.

There are many different ways parents can be offered help with their children's sleep difficulties. The most common and the one that has proven to be most effective is behavioural interventions, through groups or individual work. However, despite there often being a need for extra support, many parents find that they do not wish to attend these interventions.

This study seeks to find out, by interviewing between 8 and 12 parents of children with disabilities and sleep difficulties, the reasons parents seek help and support in the first place, and for what reasons they are likely to be involved with services.

What would taking part involve?

The research involves you being interviewed for between 45 minutes to an hour. During this time, I will ask you questions about being a parent of a child with disabilities and sleep difficulties and what it has been like to seek help for your child/children. There will be time at the end for you to ask me any questions, or to say anything that I didn't ask about.

The interview will take place at Camden MOSAIC: Integrated service for disabled children, Kentish Town Health Centre, 2 Bartholomew Road, London, NW5 2BX, between 9am and 5pm. However, if this time or place is not convenient, I am happy to think about alternatives with you. Unfortunately it is not possible to pay you for your involvement.

The interview will be recorded and transcribed, with your consent. The data from this study will be stored in encrypted files on a password-protected computer and any identifying information will be given a pseudonym. Audio-recordings and contact details will be deleted following completion of the

research. The data will be saved electronically for up to three to five years after the research is finished and may be used to write an article for publication in a psychological journal, after which point it will be destroyed.

What are the possible benefits of taking part?

There are not any specific treatment benefits. However, there may be some indirect benefits in the form of making services more accessible and useful to parents of children with disabilities who also experience sleep difficulties, and help services know how to better support parents in similar situations in the future.

What are the possible disadvantages and risks of taking part?

There are no risks involved in taking part in the research, although it is possible that you might become upset if you talk about something you have found difficult or emotional. If this happens, we can take a break from the interview, rearrange, or you can withdraw from the research at any time. If you become upset about an aspect of parenting, you could always talk to a Clinical Psychologist from the sleep service about this. Otherwise, I can give you details of other support services which are not connected to the sleep service and you could contact them afterwards. The interviews will remain confidential, unless it is revealed that you or someone else is at harm or risk of possible harm. If this were to happen, I would be obliged to break confidentiality and I would need to contact relevant services to keep everyone safe.

Further supporting information

The study is being conducted as part of my Professional Doctorate in Clinical Psychology degree at the University of East London. It has been reviewed by the University of East London Research Ethics Committee and the National Research Ethics Committee London – Central.

You are not obliged to take part in this study and should not feel made to participate. This research is separate from the support you receive at the sleep service. Although it may have been through this service that I got to know that you are a parent of a child/children with disabilities and sleep difficulties, if you

decide to go ahead with the interview you are not obliged to tell anyone you are participating and it will not affect the services you and your family are offered.

You are free to withdraw from the study at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself or your family and without having to give a reason. Should you withdraw from the study during or after the interview, your entire interview will be discarded. You can decide to withdraw at any time, but not once the study has been written up (around March 2016).

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this information sheet for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor Dr. Poul Rohleder, School of Psychology, University of East London, Water Lane, London E15 4LZ. P.A.Rohleder@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

APPENDIX I: Participant Consent Form

Central and North West London NHS
NHS Foundation Trust

University of East London
School of Psychology
Stratford Campus
Water Lane, Stratford
London, E15 4LZ

PARTICIPANT CONSENT FORM

Participant Identification Number for this trial:

Study title

Parents of Children with Disabilities: Exploring the reasons for seeking help for sleep difficulties

Name of Chief Investigator: Annie McHugh

☐ I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐ I understand that relevant sections of data collected during the study, may be looked at by individuals from University of East London, from regulatory authorities or from the NHS Trust, where it is relevant to my

taking part in this research. I give permission for these individuals to have access to my records.

☐ I agree to the recording and transcribing of the interview.

☐ I agree to take part in this study.

Participant's Name (BLOCK CAPITALS)

…….

Participant's Signature

……..

Date: ……..…….

Chief Investigator's Name (BLOCK CAPITALS)

……..

Chief Investigator's Signature

……

Date: ……..…….

APPENDIX J: Information leaflet for local Patient Advice and Liaison Service

PALS
– we're here to help you

This document is also available in other languages, large print, Braille and audio format upon request.
Email: communications.cnwl@nhs.net

Sipas kërkesës, ky dokument gjithashtu gjendet edhe në gjuhë të tjera, me shkrim të madh dhe në formë dëgjimore.

هذه الوثيقة متاحة أيضا بلغات أخرى والأحرف الطباعية الكبيرة وبطريقة برايل للمكفوفين وبصيغة سمعية عند الطلب

এই ডকুমেন্ট অন্য ভাষায়, বড় প্রিন্ট আকারে, ব্রেল এবং অডিও টেপ আকারেও অনুরোধ পাওয়া যায়

این مدرک همچنین بنا به درخواست به زبانهای دیگر، در چاپ درشت و در فرمت صوتی موجود است.

આ દસ્તાવેજ વિનંતી કરવાથી બીજી ભાષાઓ, મોટા છાપેલા અક્ષરો અથવા ઓડિઓ રચનામાં પણ મળી રહેશે.

本文件也可应要求，制作成其它语文或特大字体版本，也可制作成录音带。

Dokument ten jest na życzenie udostępniany także w innych wersjach językowych, w dużym druku, w alfabecie Braille'a lub w formacie audio

Mediante solicitação, este documento encontra-se também disponível noutras línguas, num formato de impressão maior, em Braille e em áudio.

Dokumentigaan waxaa xitaa lagu heli karaa luqado kale, daabacad far waa-wayn, farta indhoolaha (Braille) iyo hab dhegaysi ah markii la soo codsado.

நீங்கள் கேட்டுக்கொண்டால், இந்த ஆவணம் வேறு மொழிகளிலும், பெரிய எழுத்து அச்சிலும் அல்லது ஒலிநாடா வடிவிலும் அளிக்கப்படும்.

Be belge istenirse, başka dillerde, iri harflerle, Braille ile (görme engelliler için) ve ses kasetinde de temin edilebilir.

Central and North West London NHS Foundation Trust,
Stephenson House, 75 Hampstead Road, London NW1 2PL.
Tel: 020 3214 5700 **www.cnwl.nhs.uk**

March 2012

Central and North West London NHS
NHS Foundation Trust

Patient Advice and Liaison Service (PALS)

When you need advice or information about your health service, have concerns, or don't know who to ask.

PALS
– We're here to help you

APPENDIX K: Notice of Ethical Approval from University of East London Research and Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/Professional Doctorates in Clinical, Counselling and Educational Psychology

SUPERVISOR: Poul Rohleder **REVIEWER: Sharon Cahill**

STUDENT: Annie McHugh

Title of proposed study: Parents of Children with Disabilities: Exploring the reasons for seeking help for sleep problems

Course: Professional Doctorate in Clinical Psychology

DECISION *(Delete as necessary)*:

***APPROVED**

APPROVED: Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in

doubt, students should ask their supervisor for support in revising their ethics application.

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data. Student's name *(Typed name to act as signature):* Student number: Date:

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

	HIGH
x	MEDIUM
	LOW

Reviewer comments in relation to researcher risk (if any):

Reviewer *(Typed name to act as signature)*: *Sharon Cahill*

Date: 24th Feb 2015

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)

PLEASE NOTE:
*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: http://www.uel.ac.uk/gradschool/ethics/fieldwork/

9th March 2016
Dear Annie

Project Title:	**Parents of Children with Disabilities: Exploring the reasons for seeking help for sleep problems**
Researcher(s):	**Annie McHugh**
Principal Investigator:	**Annie McHugh**

I am writing to confirm that the application for the aforementioned NHS research study reference **15/LO/1352** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **9th March 2020**. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why UREC approval should be extended.

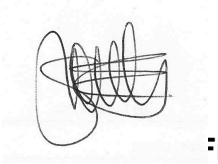
Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Trust Research Ethics Committee by emailing researchethics@uel.ac.uk.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

With the Committee's best wishes for the success of this project.

Yours sincerely,



Fieulleteau
Research Integrity and Ethics Manager
For and on behalf of
Professor Neville Punchard
University Research Ethics Committee (UREC)
Research Ethics
Email: **researchethics@uel.ac.uk**

APPENDIX L: Letters of Ethical Approval from NHS Research and Ethics Committee London – Central

NHS
Health Research Authority
National Research Ethics Service
NRES Committee London - Central
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7820

03 September 2015

Miss Annie McHugh, Trainee Clinical Psychologist
University of East London
166b Shakespeare Crescent
London
E12 6NB

Dear Miss McHugh

Study title:	**Parents of Children with Disabilities: Exploring the reasons for seeking help for sleep problems**
REC reference:	**15/LO/1352**
Protocol number:	**N/A**
IRAS project ID:	**177421**

The Research Ethics Committee reviewed the above application at the meeting held on 26 August 2015. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Elaine Hutchings, NRESCommittee.London-Central@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Additional conditions

1. Please submit an update of the schedule attached to the protocol for our records.

2. Information sheet

    a. This needs to say that the interview will be recorded and transcribed with the participant's consent. It should say how the recordings and transcriptions will be stored and for how long, and how they will be destroyed.

    b. The phrase 'which is part of my doctoral thesis' should be added to the end of the first sentence under 'Invitation and brief summary'.

    c. The word 'which' needs to be inserted between 'support services' and 'are not' under 'What are the possible benefits of taking part?'

    d. Under the same heading, the last sentence needs to be amended to read 'If this were to happen, I would be obliged to break confidentiality.....'

    e. The correct name of the reviewing NRS Research Ethics Committee needs to be given.

3. Consent form

    a. The consent form needs to follow the standard template accessible on http://www.hra-decisiontools.org.uk/consent/examples.html to include the following paragraph adapted to your study:

"I understand that relevant sections of data collected during the study may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records."

b. It needs to include a point to say 'I agree to the recording and transcribing of the interview'.

c. It needs to include a final point to say 'I agree to take part in this study'.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Social or scientific value; scientific design and conduct of the study

The schedule of stages attached to the protocol was queried and you confirmed that the dates in the schedule were incorrect. You were asked to provide an updated schedule.

Recruitment arrangements and access to health information, and fair participant selection

You were asked who will be recruited into the study and said that ideally, you will recruit an even mix of people who have dropped out from the sleep interventions and those who have completed an intervention. Suitable people will be identified by staff at Camden Mosaic who will also send out invitations to participate and information about the study, in order to protect identities.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

There were some reservations about the study since it appeared to be somewhat intrusive and might not yield benefit of significance. You were asked to advise the benefits of the study as these had not been set out in the application form. You acknowledged that there will be no direct benefit for participants but said it is hoped that there will be future benefits for parents of children with disabilities and sleep difficulties. You confirmed that it is intended to publish the results and to feedback to the Camden Mosaic sleep service which is keen for the study to take place because of its concern at the sleep intervention drop-out rate. The Committee was reassured about the potential benefits of the study.

Informed consent process and the adequacy and completeness of participant information

It was noted that participants will opt into the study by contacting you following receipt of the information about the study. You confirmed that consent will be obtained on attendance for interview.

You were advised that the information sheet needs to explain that the interview will be recorded and transcribed and say what will happen to the recordings and transcriptions with regard to storage and destruction. The wording of the limits on confidentiality requires improvement. The consent form needs to follow the model format and to include specific consent for the recording and transcription of the interviews.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*	
Covering letter on headed paper [Covering Letter]	1	06 July 2015	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEL Professional Indemnity]	1	20 July 2015	
Interview schedules or topic guides for participants	1	28 July 2015	
IRAS Checklist XML [Checklist_20072015]		20 July 2015	
Letters of invitation to participant [Invitation to Participate]	1	22 June 2015	
Other [Email with additional information]		28 July 2015	
Participant consent form	1	28 July 2015	
Participant information sheet (PIS)	1	28 July 2015	
REC Application Form [REC_Form_20072015]		20 July 2015	

Research protocol or project proposal	1	28 July 2015	
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	22 June 2015	
Summary CV for supervisor (student research) [Supervisor's CV]	1	29 June 2015	
Summary, synopsis or diagram (flowchart) of protocol in non technical language	1	28 July 2015	

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

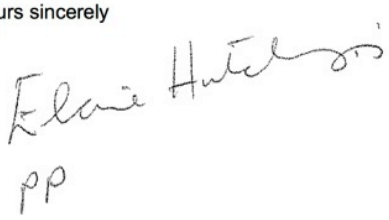
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/LO/1352	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Andrew Hilson
Chair

E-mail: NRESCommittee.London-Central@nhs.net

Enclosures:	*List of names and professions of members who were present at the meeting*
	"After ethical review – guidance for researchers"
Copy to:	*Professor Neville Punchard, University of East London*
	Miss Rubina Choudhry, NoCloR

NRES Committee London - Central

Attendance at Committee meeting on 26 August 2015

Committee Members:

Name	*Profession*	*Present*	*Notes*	
Dr Louise Abrams	Consultant Physician and Clinical Pharmacologist	Yes		
Mr Clive Carsley	Retired Lawyer	Yes	Chairing the meeting	
Ms Sally Davis	Lawyer/PhD Student	No		
Dr Beverly Donaldson	Academic Research Midwife	Yes		
Dr Olivia Festy	Clinical Trials Administrator	Yes		
Mrs Sophie Forsyth	Lawyer	Yes		
Mr Stephen Gerry	Medical Statistician	No		
Dr Frances Goodhart	Consultant Clinical Psychologist	No		
Dr Andrew Hilson	Consultant in Nuclear Medicine	Yes		
Professor Lewis Spitz	Emeritus Nuffield Professor of Paediatric Surgery	No		
Mr Benjamin Stanfield-Davies	University Lecturer	No		
Dr Gareth Tudor-Williams	Consultant in Paediatric Infectious Diseases	Yes		
Mrs Marney Williams (co-opted from Fulham REC)	Teacher	Yes		

Also in attendance:

Name	*Position (or reason for attending)*	
Elaine Hutchings	REC Manager	
Ninha Silva	Observer	

NHS
Health Research Authority
National Research Ethics Service

London - Central Research Ethics Committee
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7820

22 October 2015

Miss Annie McHugh, Trainee Clinical Psychologist
University of East London
166b Shakespeare Crescent
London
E12 6NB

Dear Miss McHugh

Study title:	**Parents of Children with Disabilities: Exploring the reasons for seeking help for sleep problems**
REC reference:	**15/LO/1352**
Protocol number:	**N/A**
IRAS project ID:	**177421**

Thank you for your letter of 9 October 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 03 September 2015

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant consent form	2	04 October 2015
Participant information sheet (PIS)	2	04 October 2015
Research protocol or project proposal	2	04 October 2015

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Covering Letter]	1	06 July 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEL Professional Indemnity]	1	20 July 2015

Interview schedules or topic guides for participants	1	28 July 2015
IRAS Checklist XML [Checklist_20072015]		20 July 2015
Letters of invitation to participant [Invitation to Participate]	1	22 June 2015
Other [Email with additional information]		28 July 2015
Participant consent form	2	04 October 2015
Participant information sheet (PIS)	2	04 October 2015
REC Application Form [REC_Form_20072015]		20 July 2015
Research protocol or project proposal	2	04 October 2015
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	22 June 2015
Summary CV for supervisor (student research) [Supervisor's CV]	1	29 June 2015
Summary, synopsis or diagram (flowchart) of protocol in non-technical language	1	28 July 2015

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/LO/1352 **Please quote this number on all correspondence**

Yours sincerely

Elaine Hutchings

Elaine Hutchings
REC Manager

E-mail: NRESCommittee.London-Central@nhs.net

Copy to: *Professor Neville Punchard, University of East London*

Miss Rubina Choudhry, NoCloR

APPENDIX M: Letter of Ethical Approval from Central North West London Foundation Trust Research and Development

noclor
RESEARCH SUPPORT

1st Floor, Bloomsbury Building
St Pancras Hospital
4 St Pancras Way
NW1 0PE

Tel: 020 3317 3045
Fax: 020 7685 5830/5788
www.noclor.nhs.uk

07 December 2015

Miss Annie McHugh
4th Floor, East Wing
St Pancras Hospital
4 St Pancras Way
London
NW1 0PE

Dear Miss McHugh

This NHS Permission is based on the REC favourable opinion given on **03 September 2015**.

I am pleased to confirm that the following study has now received R&D approval, and you may now start your research in **the trust(s) identified below**:

Study Title: Parenting a Child With Disabilities: Exploring the Reasons for Seeking Help for Sleep Difficulties
R&D reference: 177421
REC reference: 15/LO/1352

Name of the trust	Name of current PI/LC	Date of permission issue(d)
Central North West London NHS Foundation Trust	Dr Susan Cottam	07 December 2015

If any information on this document is altered after the date of issue, this document will be deemed INVALID

Specific Conditions of Permission (if applicable)

If any information on this document is altered after the date of issue, this document will be deemed INVALID

Yours sincerely,

Pushpsen Joshi
Research Operations Manager

Cc: Principle Investigator(s)/Local Collaborator(s), Sponsor Contact

1st Floor, Bloomsbury Building
St Pancras Hospital
4 St Pancras Way
NW1 0PE

Tel: 020 3317 3045
Fax: 020 7685 5830/5788
www.noclor.nhs.uk

May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with each Trust are allowed contact with that Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998.
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Serious Adverse events:** adverse events or suspected misconduct should be reported to the R&D office and the Research Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- **Publications:** it is essential that you inform the R&D office about any publications which result from your research.
- **Ethics:** R&D approval is based on the conditions set out in the favourable opinion letter from the Research Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Research Ethics Committee and R&D Office as soon as possible.
- **Monthly / Annually Progress report:** you are required to provide us and the Research Ethics Committee with a progress report and end of project report as part of the research governance guidance.
- **Recruitment data:** if your study is a portfolio study, you are required to upload the recruitment data on a monthly basis in the website: http://www.crn.nihr.ac.uk/can-help/funders-academics/nihrcrn-portfolio/recruitment-data/
- **Amendments:** if your study requires an amendment, you will need to contact the Research Ethics Committee. Once they have responded, and confirmed what kind of amendment it will be defined as, please contact the R&D office and we will arrange R&D approval for the amendment. If your study is Portfolio Adopted, amendments must be submitted for R&D review via the NIHR CRN (CSP), please refer to the Amendments Guidance for Researchers: http://www.crn.nihr.ac.uk/can-help/funders-academics/gaining-nhs-permissions/amendments/
- **Audits:** each year, noclor select 10% of the studies from each service we have approved to be audited. You will be contacted by the R&D office if your study is selected for audit. A member of the governance team will request you complete an audit monitoring form before arranging a meeting to discuss your study.